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Development and Feasibility of a Measure of Self in Dementia

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M.Phil

2018

Development and Feasibility of a Measure of Self in Dementia

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Submitted for the Degree of

Master of Philosophy

Faculty of Health Studies

University of Bradford

2018

Abstract

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Key words: dementia, selfhood, identity, autobiographical memory, cognition, psychometric measure, cued recall.

Methods

A standardised measurement tool was developed by identifying aspects of self that can be measured, and research methods that are effective at investigating self in people without dementia. The measure consists of three sets of illustrated 'I am…' statements representing *Activities*, *Traits and Physical Characteristics*, and *Relationships and Occupations*. Participants were asked to (i) sort these according to whether each was 'just like me', 'a bit like me' or 'not at all like me' (ii) sort their 'just like me' choices to identify the statement most like them; (iii) describe memories associated with this statement. The measure was tested with 20 people with dementia to inform refinement. The refined measure was tested for reliability and validity by comparing results from five people with dementia and six age-matched people without dementia.

Results

Outcome measures were *strength*, *complexity* and *quality of self* and an *'episodicity' score* reflecting the descriptive richness of memories. The initial administration to 20 people indicated that the measure was suitable for people with mild to moderate dementia, and the outcomes were meaningful and reliable. An 'Observational Framework' was developed to enable measurement of self via gestures and expressions of people with limited verbal abilities. The second study indicated that the new measure has good test-retest reliability, but convergent validity was not demonstrated. Participants with dementia demonstrated strength, complexity and quality of self scores comparable to participants without dementia. The results suggest that providing visual cues bypasses the cognitive processes required for effortful recall.

Acknowledgements

I would like to hugely thank my supervisors, Dr Sarah Smith, Professor Jan Oyebode and Professor Claire Surr; without them I could not have started, continued and finished this PhD. I must also thank the Alzheimer's Society for funding my studentship, and providing support and encouragement from my three Research Network Volunteers. My thanks also to Dr Clare Rathbone, Professor Stephen Sabat and Professor Pia Kontos who generously acted as my expert advisors; all their advice was very valuable. Also huge thanks to my husband, Tim, for his patience and for acting as my driver. Without him I could not have visited the many towns and villages where my research participants attended support groups, and the places where they lived. I would also like to thank the many dementia support group organisers, care home managers and care staff who helped me approach participants for my studies. But my biggest thanks go to the lovely participants who welcomed me into their homes and willingly allowed me to interview them, and provided me with some wonderful memories.

Dedication

This thesis is dedicated to the memory of my mother, Winifred Mary Joan Clapham. She lived with dementia for approximately eight years, and was the motivation for all my steps along the road to completing this PhD. It is also dedicated to my granddaughter, Matilda Grace, who I hope will grow up during a time when dementia is no longer stigmatised.

Table of Contents

List of Figures

List of Tables

List of Appendices

Glossary

Autobiographical memory: memory that contains information about oneself, and about personal experiences.

Biopsychosocial approach: considers biological, psychological, and social factors and their complex interactions in understanding health, illness, and care practices.

Dementia: an overall term that describes a group of conditions associated with decline in memory or other thinking skills, severe enough to reduce a person's ability to perform daily activities.

Alzheimer's disease: a degenerative brain disease that is the most common form of dementia. Symptoms are progressive memory loss, impaired thinking, disorientation, and changes in personality and mood that cannot be attributed to other diseases or brain disorders.

Dementia with Lewy Bodies: a progressive condition in which symptoms include confusion, memory problems, mood changes, difficulty with everyday tasks, spatial awareness problems, slowed movement and stiffness, tremors, visual hallucinations and delusions. It is the third most common form of dementia.

***Fronto-temporal dementia*:** a condition that affects the frontal and temporal cortical areas of the brain. It can be distinguished from other forms of dementia by personality change and impaired ability to regulate personal behaviour (Levine, 2004).

Semantic dementia: a neurodegenerative disease characterised by semantic memory loss including general knowledge and knowledge of objects. There are also language deficits such as impaired word finding and comprehension (Duval et al, 2012).

Vascular Dementia: areas of the brain are affected by mini-strokes. The disease progresses in a stepwise, uneven rate of decline, and memory may be affected early in the disease (Mills, 1998). It is the second most common type of dementia.

Language, expressive: the ability to put thoughts into words and sentences that make sense and are grammatically correct.

Language, receptive: the ability to understand the words, sentences and meaning of what others say or what is read.

Memories, episodic: unique memories of events that are specific in time, place, and context (who, what, where, or why) that can be stated explicitly.

Memories, semantic: general world knowledge and basic facts that a person accumulates over a lifetime.

Memory, long-term: a memory store with unlimited capacity memory that can retain information over lengthy periods of time.

Memory, short-term: a small amount of information that is held in mind for a few seconds. Information can be held and available for recall, but not manipulated. When effort is made to remember the information it passes into long-term memory.

Mild cognitive impairment: a condition characterised by minor problems with mental abilities such as memory or thinking. Problems are worse than would normally be expected for a person of similar age but not so severe as to interfere significantly with daily life, and are not diagnosed as dementia.

Objective: the state of not being influenced by opinions or personal feelings when representing facts.

Personality: the set of personal characteristics that influence a person's thoughts, actions, emotions and beliefs.

Person-centred care emphasises a person's social and psychological needs in addition to their medical and physical needs, It nurtures remaining abilities and seeks to promote sense of self. The focus is an ongoing process of personalised care that is revised to meet the changing needs of the person (physical, psychological and social), and thus support a person's sense of self.

Personhood: a standing or status that is bestowed upon one human being by others in the context of relationship and social being. It implies recognition, trust and respect.

Psychosocial interventions: non-pharmacological therapeutic ways to support people to maintain mental and physical wellbeing.

Retrieval, direct: memories come to mind spontaneously activated by specific cues.

Retrieval, generative: memories are actively and consciously constructed.

Self-awareness: being aware of different aspects of the self including behaviours and feelings at a particular time. Essentially, it is a psychological state in which one’s self becomes the focus of attention.

Self-concept: the collection of beliefs about oneself. Generally, self-concept embodies the answer to "Who am I?".

Self-consciousness: the tendency to introspect and examine one's inner self and feelings.

Subjective: the state of being influenced by personal feelings or beliefs.

1 Introduction

"Self is the core of who we are as an individual, as a person,
as a human- no disease can take that away" (Fazio, 2013, p.18*).*

1.1 Background

Fazio's quotation encapsulates the essence of this study; the belief that self is a vital and enduring aspect of all human beings. It has been suggested by some that dementia may bring about changes in self, or how self is expressed, which may be brought on by the condition and people's resultant altered lived experiences. There are now 50 million people worldwide living with dementia, who will require psychological, biomedical and social support. The majority of this support is currently provided by families, with an estimated global societal and economic cost of £650 billion per year (WHO, 2018). Thus, dementia has been identified as a public health priority that requires policy change to enhance the treatment and care of people with dementia, including psychosocial treatments designed to enhance well-being and personhood in dementia.

1.2 Introduction

The aim of this thesis is to develop an objective measure of self in people living with dementia. Drawing on the principles and methods of cognitive psychology it will take the form of a standardised measurement tool that can be used to assess or measure retained self, and any changes in self over time. It is hoped that in the future the measure will be useful to dementia practitioners and researchers for evaluating the efficacy of psychosocial interventions and informing care approaches that are supportive of self. The aim is that the proposed measure will recognise the personal nature of self and will be able to capture, in a robust manner, the subjective, expressed sense of self of a broad range of people living with dementia.

This introductory chapter starts by providing a definition of self that will be used throughout this study. It will also introduce a range of self-related concepts such as identity, personality and personhood, and explain their relationship to theories of self as well as their implications or application within the proposed measure of self. An overview of why maintaining self is important for people

with dementia will then be presented, thus providing a strong rationale for why a tool to measure self is needed. The chapter will then outline how self has been studied in people without dementia and how this contributes to our broader understanding of self and its measurement, as well as critiquing relevant general theories of cognitive psychology, and how they inform theories of how conditions such as dementia affect sense of self. Following this, arguments will be presented to support the position that there are currently no existing tools appropriate for measuring self in people with dementia due to a range of issues associated with tool design and administration. It will outline how the range of existing measures of self in people without dementia provides a starting point for the design of a tool that can successfully measure self in people with dementia.

1.3 What is self?

Self is a concept that has been studied from a broad range of philosophical and methodological standpoints. There are a wide range of definitions of self and a range of terms (e.g. identity, personhood, self-concept, personality), which authors from different disciplines appear to use interchangeably with the term self. These different terms and their relationship to the concept of self will be discussed in this section. However, the definition of self that will be used within this study will be presented first.

William James, the eminent philosopher and psychologist took a broad view of self that incorporated philosophical and psychological stances. His view has continued to have a strong influence on the psychology of self up to the present day; this project will adopt James's definition of self:

> *"a man's Self is the sum total of all that he CAN call his, not only his body and his psychic powers, but his clothes and his house, his wife and children, his ancestors and friends, his reputation and works, his land and horses, and yacht and bank account. All these things give him the same emotions"*
> *(James, 1890, p.292).*

This definition fits well with what is already known about self in dementia. As will be discussed in Chapter 2, existing research on self in dementia has focused on a broad range of embodied, psychological and social processes, experiences and behaviours. Therefore, a definition of self which reflects the multifaceted

nature of self, including the context of the lived experience of dementia is required. James' definition of self fits this requirement because it argues that self should not be regarded as a single entity that originates from within the individual only; but that is inclusive of social and cultural factors that contribute to how an individual constructs his or her self.

James's definition is consistent with the biopsychosocial model that underpins current best practice in dementia care. Good quality dementia care is defined as care which is holistic and addresses the full range of physical, psychological and social needs of the person with dementia (see section 1.6). The definition includes aspects of self that can be described objectively, such as physical appearance, family and social relationships, cherished possessions, favourite places and previous occupations, and those that can be described subjectively by a person with the ability to do so, such as a person's beliefs, values, and memories. These should all be incorporated into a measure, tailored to the lifetimes of experiences of people with cognitive change.

The broad range of research on self has meant that there is a range of definitions of self, self-concepts, and dispositions associated with the term (see glossary). The terms identity and personhood require a fuller explanation since they are particularly important for understanding self in people with dementia. Firstly, identity is defined as knowing "who one is, in cognition and feeling. It means having a sense of continuity with the past; and hence a 'narrative', a story to present to others" (Kitwood, 1997b, p.8). Other researchers regard identity as a sub-component of self that represents continuity via self-knowledge and life history (e.g. Addis & Tippet, 2004), thus an agreed feature of identity appears to be that it is based on a continuous narrative that includes locating an individual in time (Medved & Brockmeier, 2008), emphasising the importance of personal memories and a sense of time.

Personhood is "a standing or status that is bestowed upon one human being by others in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997b, p.8), and emphasises the importance of interpersonal communication (Davis, 2004). Thus personhood highlights how interactions with other people contribute to the individual sense of self. Kitwood (1997b, p.45) describes how "malignant social psychology" can undermine the personhood of people with dementia if people who care for them disempower

and depersonalise them. This may happen because people with dementia are regarded as having less value than people without dementia. The concept of personhood relates to “person value” (Skeggs, 2011, p.503) which includes moral worth as well as the economic value of being able to work and accrue property and capital. Thus some individuals (e.g. people without work or pensioners) may be regarded as ‘use-less’ because they only consist of “lacks and gaps, voids and deficiencies” (Skeggs, 2011, p.503). With regard to the worth of people with dementia, Kitwood (197b, p.8) took the view that every person continues to have absolute value, and should be treated with respect, and this is not dependent on their actual or perceived economic status or other contribution to society.

Recognising personhood is a key requirement of high quality person-centred care (see also section 1.6) and underpins approaches that recognise the importance of the person as an individual. It highlights the social aspects of self that result from interactions with other people and which also contribute to the personal sense of self, helping people with dementia to continue living as full a life as is possible. It has been claimed that maintaining each aspect of self is vital for humans because all aspects are associated with psychological and physical well-being (Sedikides et al, 2013).

1.4 Why do we need to measure self in people living with dementia?

Self can be considered as the core of an individual and having a sense of self enables a person to be valued as an active member of society (Fazio, 2013). Loss of self is regarded anecdotally as the most feared consequence of dementia, and is thought to result from memory loss and cognitive decline associated with the condition, (Orona, 1990; Corner & Bond, 2004). However, these beliefs draw on a narrow, cognitive and memory based definition of self; this chapter proposes that self includes, but is not limited to, having retained memories. Research into the impact of dementia on self is important in supporting this position because studies have demonstrated that some aspects of self are retained by people with dementia even when cognitive impairment is severe, and thus any measure of self in dementia must look beyond memory (Cadell & Clare, 2013).

Thus there are theoretical, practical and ethical reasons for measuring self in people with dementia. These investigations will contribute theoretically to the ways in which self is affected by dementia, as well as enabling assessment of whether care interventions help maintain self in people with dementia, and contributing to the case for valuing people with dementia as equal members of society. These will be explored in more detail below.

1.5 Theoretical views of self

The theoretical views of self that will be investigated in this thesis are essentially cognitive and socially focused. Cognitive psychologists examine mental processes, such as memory and emotion, employing experimental research methods, and often using questionnaires or structured interviews as measurement tools. For example, people may be asked to describe memories of personal events and how they feel when they recall these events. By asking people how old they were when events occurred, where they were living and other facts about themselves it has been demonstrated that sense of self is related to their memories (for example, Conway, 2005). In some instances, people may have difficulty recalling memories in their totality but may be able to access sensations associated with the memory; these have been called subjective feelings. It has been demonstrated that subjective accounts of feelings associated with the recall of memories can be captured experimentally (Tulving, 2002; Piolino et al, 2006). For example, people describe a ‘tip of the tongue’ feeling, when they can very nearly remember a fact or an event, which is different from not knowing anything about the fact or event. Thus study of subjective feelings associated with memory is a valid focus of study (see Souchay 2007 for a review) which may be useful for understanding self.

Cognitive psychologists who have evidenced theoretical models of self by comparing cognitively healthy participants with people who are known to have specific cognitive impairments, demonstrated that some deficits in self may be related to particular cognitive impairments. For example, it has been shown that people who have impaired autobiographical memory also have a weakened self-concept, by using measures of self that require recollection of memories relevant to self-concept (Addis & Tippet, 2004). Studies of this kind tend to include participants from clinical populations who have been diagnosed with neuropsychological conditions, such as Alzheimer’s disease and other forms of

dementia. They have identified specific types of memories that contribute to a sense of self. Some of the most recent studies will be presented more fully in Chapter 2.

Socially focused studies have demonstrated that some aspects of self remain largely stable over a lifetime, whilst others are more fluid. For example, research has demonstrated that identity evolves over time and adapts to changes associated with ageing (Fazio, 2008). Thus, aspects of self may change over the course of a lifetime, but evidence suggests that a core self remains the same. The current Measure of Self will attempt to identify changes in self as well as the ways in which self is stable, with relative stability or change depending partly on personality traits and lived experiences (Kitwood, 1997a). This demonstrates the complexity and interconnectedness of various components of self.

There is also a temporal aspect of autobiographical self such that self has a trajectory of past, present and future. In order to anticipate oneself in the future one must have access to a personal past (Bassett & Graham, 2007). Thus one's sense of self and continued identity is supported by one's memories and life story, and being aware of one's life story requires a continuous sense of self (Conway et al, 2004), again demonstrating the interconnectedness of autobiographical memory, identity and self. Figure 1.1 summarises theoretical views of self and demonstrates how these can help answer questions concerning aspects of self that change with age and aspects that remain stable.

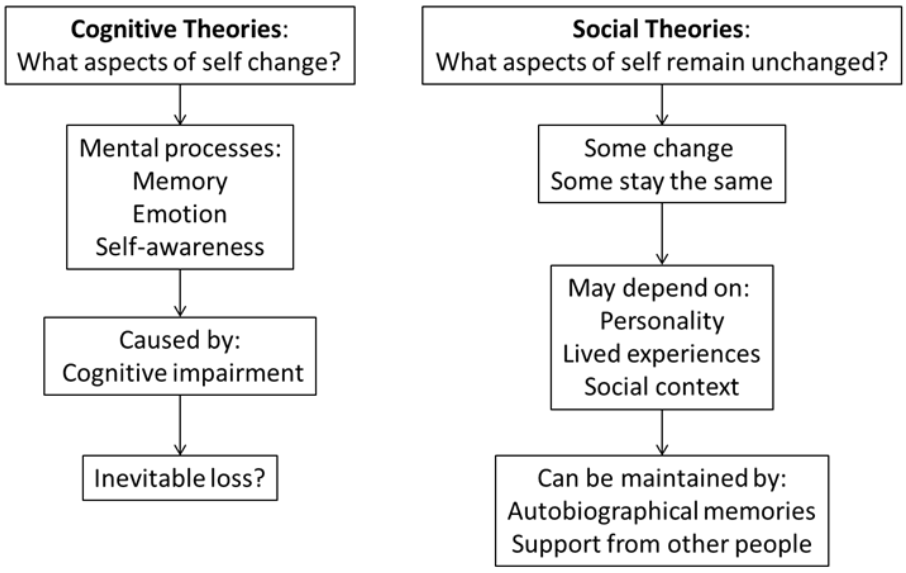


Figure 1.1: Theoretical Approaches to Change in Self

Drawing these theories together, in order to develop a new measure of self, a theoretical model or framework of self has been developed as part of this doctoral research, which underpins the measure and its component parts. It is a multifaceted model of self developed by examining multidisciplinary theories in more detail, along with evidence that relates to the aspects of self identified in the earlier definition. This will be presented in Chapter 2.

1.6 Practical needs for supporting self in people living with dementia

Maintaining and supporting positive feelings about one's self is a fundamental human need. Maintaining a positive sense of self throughout the lifespan is facilitated by frequent validation and support (Charmaz,1983), and for people with dementia, this validation and support is increasingly provided by other people as the condition progresses, most importantly by care givers. It is recognised that the traditional 'medical' model of task-based care is not appropriate for people with dementia because this method of care fails to recognise the person and thus to support the self (Fazio, 2013). Kitwood (1997a) claimed that this traditional method of care cannot meet the psychological needs of the person, one of which is maintenance of identity. Kitwood (1997b) proposed a method of care, called person-centred care, which was founded on the principle of personhood, which, as defined above, emphasises the importance of social relationships for the formation and maintenance of self. The person-centred approach to care emphasises a person's social and psychological needs in addition to their medical and physical needs. Instead of focusing on the cognitive losses associated with dementia, person-centred care nurtures remaining abilities and seeks to promote sense of self. Being sensitive to a person's remaining sense of self means that the focus of person-centred care is the development of an ongoing process of personalised care that can be revised to fit the changing needs of the person (physical, psychological and social), and thus support a person's sense of self (Tappen et al, 1999).

Personalised care methods can be enhanced by therapeutic interventions designed specifically to meet the needs of people with dementia. There is now a world-wide 'dementia plan' that states a commitment to improve the lives of people with dementia, their families and carers (WHO, 2018). This study addresses the need for new methods of evaluating innovative solutions. There

are still no pharmaceutical drugs that can cure dementia, or any treatment to permanently prevent worsening or slow the course of the condition. Therefore, a range of psychosocial interventions have been developed (Vernooij-Dassen et al, 2010), such as reminiscence and life-story work. These kinds of interventions are intended to improve quality of life and enhance cognition and functioning, and reduce rates of institutionalisation (Moniz-Cook et al, 2011). In order for psychosocial interventions to be accepted as beneficial and thus widely adopted in health and social care they must be rigorously evaluated to examine their efficacy and cost effectiveness (Woods, 2003). The 'gold standard' for evaluating interventions is evidence from large scale randomised controlled trials (RCTs). However, there are currently few outcome measures that fully capture the non-clinical benefits of psychosocial interventions (Woods & Russell, 2014), such as maintenance of self. This study will provide a measure that can fill this gap, based on theories of self that have been identified and evaluated in the literature review, and which is tailored to the abilities and strengths of people living with dementia.

1.7 Ethical considerations

As described above with relation to personhood, an ethical requirement of person-centred care is to value and respect the individuality of persons (Kitwood, 1997b), and so maintain their standing in society. This standing should not be negated by needing to be cared for by others, or the presence of impaired cognitive abilities. One way to fulfil this ethical requirement is to enable people with dementia to communicate their subjective experiences (Kitwood, 1997a, Nordenfelt, 2014) and thus give them a voice in their own care, in research and within broader society. Development of a new measurement tool that is tailored to the abilities of the individual, will enable people with dementia to be given a voice to help articulate their own sense of self.

1.8 What are the issues surrounding existing measures of self in dementia?

The small number of experimental studies to date measuring self in people with dementia have demonstrated important relationships between self, identity and autobiographical memory (e.g. Jetten al, 2010), and have shown that some specific aspects of self may be reduced more than others in people with dementia (e.g. Addis & Tippet, 2004). However, an issue with these studies is

that they adopt a deficit focused approach in order to inform our theoretical models of self, rather than aiming to capture elements of self that are retained. In addition, there are potential issues with the methodological approaches, which may lead to skewed detrimental performance for people with dementia.

Typically, people living with dementia face challenges in meeting the conditions of applied experimental psychology research. For example, Sabat et al (1999) identified problems likely to be experienced by people with dementia who were asked to complete questionnaires investigating self-esteem. These problems included:

- Restricted vocabulary and options for response.
- Restricted social context.
- Effects of dementia that impair the person's cognitive abilities to comprehend questions and reply explicitly.

Qualitative studies exploring self in dementia (e.g. MacRae, 2010; Sabat & Harre, 1992; Small et al, 1998), reviewed in more detail in Chapter 2, have shown self to be maintained in people with dementia across the full spectrum of severity of the condition. Therefore, this study will aim to develop a measure of self that is robust, and can be administered in ways that are sensitive to the abilities of people with dementia, by drawing on techniques and approaches from qualitative research, and combining these with robust processes for measurement development, design and administration from cognitive psychology.

In short, a new measure of self designed specifically for use with people with dementia is needed in order to evaluate psychosocial interventions that are now being developed because i) pharmaceutical interventions are not effective, and ii) to provide better standards of care. There are currently no outcome measures that are suitable for testing the efficacy of these interventions (Vernooij-Dassen et al, 2010). In order to develop a new measure that will be considered effective for this purpose, this project draws on the existing body of evidence related to the design and development of measurement tools focusing on self and identity for people without dementia, with the unique approach of identifying potentially novel ways of administering the tests that are more suitable for people with dementia. This entails combining approaches from cognitive and socially focused disciplines. This methodology of integrating

approaches is new to this field of research and follows epistemology advocated by Goldman (1986) who proposes the combination of cognitive and social knowledge. This approach will be explained more fully in Chapter 3.

1.9 Summary

This project addresses gaps in existing knowledge concerning self in dementia by:

- Combining findings from psychological, cognitive and sociological research to provide a conceptual framework of self in people with dementia that can be used to develop a multi-faceted measure of self suitable for use with people with dementia.
- Using approaches to rigorous data collection that meet the requirement of robust measurement within cognitive psychology, but which are likely to maximise the performance of a person with dementia and thus provide a better measure of self in people with the condition.

An objective measure of self is needed in order to:

- Measure the experience of self in people with dementia because maintenance of self is central to good quality person-centred care.
- Provide a solution to the problem that there is currently no way to evaluate psychosocial interventions.
- Provide a basis for further research involving self and dementia.

There is currently no suitable measure for people with dementia because:

- Existing cognitive measures are not designed for identifying retained self.
- They are typically administered under strict experimental conditions that are inappropriate for people with dementia.

Thus this project will contribute to existing knowledge by providing a new holistic framework of self relevant to people with dementia and by designing a novel and robust measurement tool sensitive to the abilities of people with dementia. The literature review will be presented in Chapter 2, to provide a broad overview of what happens to sense of self in people with dementia.

2. Literature Review: Theories and Models of Self in Dementia

Even the everyday tales about shopping or the drudgery of unfulfilling work help us see the real person behind the dementia. Assembling the stories took no great skill beyond time and patience and a willingness to make an effort after meaning. (Clegg, 2010, p.13)

2.1 Introduction

The aim of this chapter is to explore via a literature review what is already known about self in dementia as interpreted by four broad theoretical approaches: cognitive, personality, social, and embodied selfhood. This chapter argues that a multifaceted view of self is most appropriate for explaining and understanding what happens to the sense of self of a person with dementia. The literature review includes studies focusing on self in people with various types of dementia in order to gain a broad view of how concepts of self in dementia have developed. It investigates how researchers from different disciplines have highlighted and explored different aspects of self in people with dementia, and how these aspects of self are expressed by people with dementia.

There will be an overview of the theoretical approaches (cognitive, personality, social, and embodied selfhood) followed by outlining the search process that identified studies for inclusion in the review. Critical reviews of the studies are organised so that the results relating to the four theoretical approaches are reviewed in turn. The chapter will end by introducing a conceptual model of self that will form the basis of the new work reported in the thesis.

In short, this chapter will locate, summarise and evaluate literature that investigates what is known about self in people with dementia and will position this with relation to underpinning theories of self, in order to help to explain and contextualise what is already known.

2.2 Theoretical approaches related to self

The first theoretical approach discussed below relates to cognitive psychology. Areas of this discipline that relate specifically to the self are outlined, together with models of self that have emerged from research following this approach. Much of the research relies on memory recall, therefore, conditions that aid and

hinder recall of specific memories are also considered. Finally, the feelings that a person may experience when remembering an event are discussed.

2.2.1 Cognitive theories specifically related to self and memory

A common early symptom of Alzheimer's disease is memory loss, hence cognitive psychology researchers who have studied self in dementia have tended to focus on the impact of changes in memory on sense of self. This reflects the widely held view that sense of self depends on our ability to subjectively remember our past lives (Schacter,1996). Another widely accepted view is that memory is not a single entity, but is made up of multiple systems, therefore Alzheimer's disease provides a useful model for studying different types of memory because of the nature of memory changes associated with the disease. Research studies that have investigated these changes are included in the literature review. Broadly, memory can be divided into short-term and long-term memory. Psychologists (for example, Baddeley, 2004) describe short-term memory as the information that is stored in the mind for very brief periods of time. Much of this information is forgotten quickly, but some is retained and memorised as part of the long-term memory system (this is different from the more widely used lay understanding of short-term memory that consists of memories that are retained for a day or so). However, the psychologists' interpretation of short-term memory has not been shown to be related to sense of self so this chapter will focus on long-term memory only.

Long-term memory can be subdivided as shown in Figure 2.1:

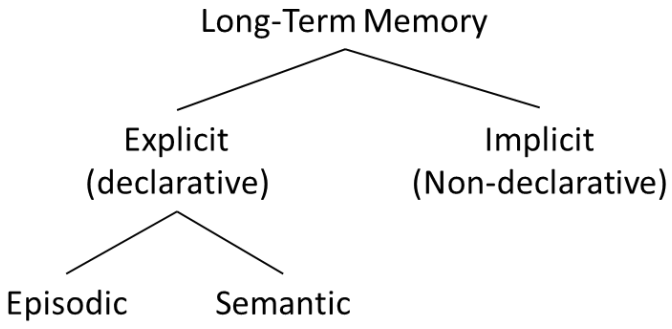


Figure 2.1: Long -Term Memory Structure

Tulving (1985) was the first researcher to put forward a theoretical model of a long term memory system consisting of explicit and implicit memories, with explicit memories further divided into episodic and semantic memories. This has

continued to be an influential model that has been used as a basis for many research studies. Tulving described explicit memories as those that can be consciously recalled and articulated (hence 'declarative'), such as facts about oneself and one's experiences in the wider world. Implicit memories are retrieved unconsciously and include procedural memories such as riding a bicycle or touch typing.

As stated above, explicit memories can be divided into episodic and semantic sub-systems. Episodic memories are those that are recalled with an awareness of when, where, how, or why the event occurred; its context, and a feeling at the time of recall that one was present at the event when it occurred (Tulving, 2002), for example a vivid memory of one's honeymoon in Paris. Semantic memories are those that are recalled with no awareness of when or how they were first remembered or learnt. For example, knowing that Paris is the capital of France is semantic (or general) knowledge. However, semantic memories can also be pertinent to the self, for example, knowing one's date of birth and where one was born, and describing characteristics and traits, such as being a caring person (Klein & Nichols, 2012). Long term memory as a whole that pertains to past personal events can also be described as autobiographical memory. Autobiographical memory consists of episodic and semantic memories that are specifically related to an individual's life story and are considered fundamental to the experience and continuity of self over time (Conway and Pleydell-Pearce, 2000).

2.2.2 A model of memory: The Self Memory System

Conway and colleagues (Conway & Pleydell-Pearce, 2000; Conway et al, 2004; Conway 2005) proposed a model that describes the associations between autobiographical memory and self, namely, the 'Self Memory System' (SMS). This model has been drawn from a wide range of autobiographical memory research. It describes the cognitive processes that underpin memory, specifically how and why we remember events as autobiographical memories (Conway & Pleydell-Pearce, 2000). There are alternative models of memory systems, notably the 'modal model' which was conceptualised by Atkinson & Shriffin (1968), and consists of three stores of sensory, short-term, and long-term memories. Memories are stored depending upon how many times they are repeated or rehearsed. However, the SMS is a more contemporary and widely

accepted model which is also more relevant to this study because of the clear relationship it suggests between self and autobiographical memory, as described below.

The SMS is theorised as consisting of the working self and the autobiographical knowledge base. Autobiographical knowledge comprises semantic and episodic information. It is proposed that the working self plays a major role in the encoding and re-construction of autobiographical memories ensuring they are consistent with and support personal goals, motivations and self-images (Conway & Pleydell-Pearce, 2000). Autobiographical knowledge is conceptualised as consisting of a base, or records, of semantic events organised by lifetime periods over three levels that connect to a bank of episodic memories. The first level of the autobiographical knowledge base comprises 'general events' that span relatively short time periods such as weddings or funerals. The second level of 'lifetime periods' is made up of longer time units that reflect particular goals, such as undergraduate study, academic career and so on through one's lifetime. A third level is 'life story schema' which represents an individual's life as a whole, constructed within a particular culture at a particular time; for example, life as a working mother in 20th century Britain. The bank of episodic memories is conceptualised as being separate from the autobiographical knowledge base, therefore, these memories are harder to recall, and more easy to lose (Conway, 2005).

The SMS model also provides a framework to suggest how memories are recalled. Figure 2.2 (adapted from Conway, 2005) illustrates how the three levels of the autobiographical knowledge base link with the episodic memory bank. It also illustrates that information is not arranged temporally, instead it is theorised that information is organised around experiences that are personally important.

The diagram illustrates how memories can be recalled once they have become part of the autobiographical memory system. Bi-directional interconnections between levels help to explain two methods of memory recall, namely generative and direct retrieval (Conway & Pleydell-Pearce, 2000). Generative retrieval is initiated by a conscious need or desire to remember an event or piece of knowledge. When recall of the general event is triggered, connections

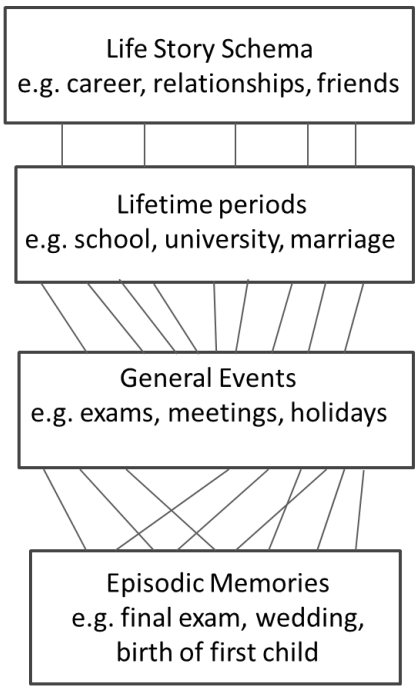


Figure 2.2: Autobiographical Memory System (Conway, 2005)

are made between relevant lifetime periods and life story schema, and a retrieval path will be formed that 'drills down' to more specific layers, and is followed to specific events in the episodic memory bank (Haque & Conway, 2001). This method of generative retrieval becomes impaired in people with dementia (Greene et al, 1995) which emphasises the point made in Chapter 1 that methods requiring generative memory retrieval are inappropriate for helping people with dementia access their autobiographical memories. Alternatively, direct retrieval is experienced as an unexpected or spontaneous memory that occurs in response to a specific trigger such as a familiar aroma or piece of music (e.g. McDermott et al, 2014; Ward & Campbell, 2013). It is believed that these memories occur because a strong stable pattern of retrieval has been established by repeated activation over time and so the memory can be directly triggered by an environmental cue. Taken together these findings imply that deliberate generative recall of episodic memories in dementia is impaired but relevant cues or prompts can spontaneously evoke autobiographical memories.

It is important to note that the methods of memory retrieval described in the SMS are not the only proposed methods of memory retrieval. Alternative theories describe associative retrieval processes, which include chaining theory and retrieval context theory (Kahana et al, 2008). However, it is beyond the

scope of this thesis to delve more deeply into these theories which are not specifically associated with the self.

2.2.3 A phenomenon that aids memory retrieval: The Reminiscence Bump

The 'reminiscence bump' phenomenon has been investigated in many studies, demonstrating that middle and older–aged adults remember a larger than expected number of memories (compared with other time periods) from a period bounded by adolescence and early adulthood (approximately 15 to 30 years of age). As yet there is no agreed explanation for the phenomenon, although Elnick et al (1999) noted that the reminiscence bump coincides with a period of intense psychological processing of memories at this time, and Rathbone et al (2008) suggested that the reminiscence bump occurs because a cluster of memories form that are related to self-images that remain easily accessible to the rememberer in the later years of life. In the context of the SMS these findings suggest that if access to these memories is impaired by conditions such as Alzheimer's disease, their associated self-images will also be weakened, meaning that there will be a correspondingly weaker sense of self. Conversely, it is possible that memories from the reminiscence bump era may continue to be more easily accessed in the face of impairment for people with Alzheimer's disease and dementia.

2.2.4 Experimental conditions that hinder memory retrieval

There may, however, be other explanations for poor access to autobiographical memories and the weakened sense of self associated with this. Some experimental studies have sought to investigate the nature and extent to which dementia affects memory recall. However, experimental procedures may cause overestimation of findings indicative of deficits in self in dementia because the experimental method has not been designed or validated for use with people with cognitive impairment, and findings may therefore reflect the impact of the experimental requirements rather than true decline in selfhood.

2.2.5 Subjective states associated with memory recall in people living with dementia

The subjective experience associated with memory recall is termed recollective experience. Investigating subjective states such as these help with understanding how individuals experience a sense of self. As outlined in

section 2.2.1, Tulving (1985) proposed a memory system consisting of three types of memory: episodic, semantic (explicit) and procedural (implicit). Tulving also proposed a way of differentiating memory systems in terms of the kinds of consciousness that characterised the experience of remembering. In simple terms, procedural memory is characterized by anoetic consciousness (no conscious awareness of remembering something), semantic memory by noetic consciousness (remembering something with no memory of when, where or how it was learnt), and episodic memory by autonoetic consciousness (remembering personally experienced events, with senses and emotions associated with being at the events). Figure 2.3 illustrates the relationships between memory systems and types of recollective experience.

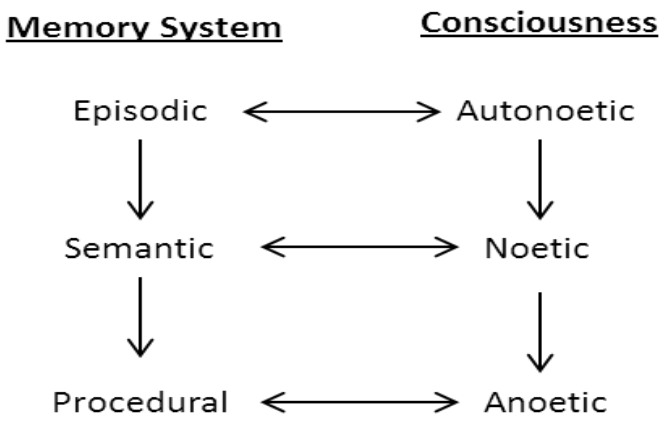


Figure 2.3: Schematic Arrangement of Three Memory Systems and Three Kinds of Consciousness (Tulving, 1985)

It is possible to experimentally determine a person's recollective experience by asking if they remember an event with details that make the event unique, or if they just know that it happened. These recollective experiences are associated with episodic and semantic memories respectively.

Having stated that Tulving was the first researcher to propose a theoretical model of long term memory, it is interesting to note that in 1804 the philosopher Maine de Biran proposed three different types of memory, consisting of mechanical, sensitive, and representative memories; he also described differences between implicit and explicit memory. He defined mechanical memories as unconscious expressions of repeated movements, representative memory as conscious recollection of ideas and events, and sensitive memories

as feelings (Schacter,1987). This memory system has never been widely recognised by experimental psychologists but correlations can be made with Tulving's memory systems; namely mechanical with procedural memories, representative with declarative memories and sensitive memories with recollective experience.

The next section focuses on personality theories and demonstrates that personality is a component of self that affects how a person visualises him or herself, and how he or she presents him or herself to others.

2.2.6 Personality Theories: Overview of personality change in people with dementia

Personality refers to the set of characteristics that influence a person's thoughts, actions, emotions and beliefs. These characteristics are conceptualised as stable traits that are distinguishing features of how a person thinks and acts, and which combine to make a person unique and provide a recognisable identity over long periods of time (McAdams, 1996). Kitwood (1997) wrote that many relatives and friends of people with dementia talked about changes in personality, leading them to feel as if they had lost the person they used to know. It has also been suggested that people with dementia show change in personality alongside, and sometimes before, other clinical signs of dementia (Robins Whalin & Byrne, 2010), although this is not universally agreed (Sabat, 2005). When people with dementia are asked to describe their own personality traits, they may base their self-description on their pre-morbid characteristics, as the cognitive changes of dementia may have prohibited them from updating their self-concept after the onset of the condition. However, various reasons why change may occur have been investigated and these will be presented and critiqued in the next section.

2.2.7 Measuring personality over a person's lifetime

Researchers have identified and investigated large numbers of personality traits and characteristics which have been incorporated into personality questionnaires. This illustrates that personality is an extremely complex entity that may be difficult to measure in people with dementia. Measures administered to both people with dementia and their relatives or carers have tended to be shortened versions of personality inventories (e.g. Ruby et al,

2009). These may rely on observable traits and characteristics (such as sociability, being organised or impatient) so that proxy ratings can be used. They may also omit traits that are more difficult to quantify. In relying on observable and readily quantifiable characteristics they may ignore other traits and characteristics necessary to provide a fuller picture of an individual (for example, time spent daydreaming, feeling guilty or willingness to compromise).

There has been much debate concerning stability or change in an individual's personality over their lifetime, centring on whether personality is wholly innate (and therefore unchangeable) or changed by environmental circumstances, i.e., whether it is stable or evolves over a lifetime. Norman (1963) hypothesised that descriptions of personality could be incorporated into five domains, and Costa and McCrae (1992) adopted these domains to produce a Five Factor Model of Personality. Costa and McCrae proposed that the traits that constitute the five domains are as follows:

1. Openness-to-experience includes traits relating to fantasies, aesthetics, feelings, actions, ideas and values.
2. Conscientiousness relates to competence, order, duty, achievement, self-discipline and deliberation.
3. Extraversion includes warmth, gregariousness, assertiveness, activity, seeking excitement and tenderness.
4. Agreeableness relates to trust, straightforwardness, altruism, compliance, modesty and tenderness.
5. Neuroticism equates with anxiety, angry hostility, depression, self-consciousness, impulsiveness and vulnerability.

Costa and McCrea (1992) developed a questionnaire, the NEO Personality Inventory (consisting of 240 questions) to aid their research into personality, and found substantial evidence to support their view that traits are stable over long time periods and can be found across cultures, and that traits can predict behaviour and experiences. However, in a later paper, McCrae et al (2000) modified their perspective. They reiterated that innate personality traits follow prescribed paths largely independent of environmental influences, but also acknowledged that there may be exceptions to this rule, and that personality change may occur as a result of life events, such as traumatic events or

exceptionally memorable experiences. Rothbart et al (2000) supported this view, proposing that traits emerge from genetic inheritance that influences, and is influenced by, the lifetime experiences of each individual. It can be argued that a diagnosis of dementia, and the resulting change in circumstances, are events that might lead to personality change.

Caspi and Roberts (2001) provided more detail about how and when personality may change across the lifespan. They reviewed longitudinal studies to determine types of continuity and change, and factors that may aid stability and change such as changing or stable environments and the way a person reacts to environmental change if it occurs. They concluded that personality continues to develop until 50 to 60 years of age, but is most likely to become stable at around 50 years. However, the changes associated with onset and diagnosis of dementia usually occur after the time of 50 to 60 years of age (when personality is said to stabilise) and therefore dementia may disrupt this period of stability.

Caspi et al (2005) also reviewed stability and change in personality emphasising how life changes and role transitions can affect personal development. This perspective prioritises the view that personality is fluid and prone to change, especially during periods of rapid physical, cognitive and social change, all of which may be typical of what can happen to a person after being diagnosed with dementia. Referring to the Five Factor Model, Caspi et al suggested that certain personality types are more or less prone to change or stability across the lifetime. For example, if levels of agreeableness, conscientiousness and emotional stability increase with age, these are likely to foster stability and ability to cope with life's challenges. However, research suggests these are amongst the traits most likely to change in Alzheimer's disease (Robins et al, 2011). This supports the suggestion above that the premorbid personality of a person diagnosed with dementia may affect the way they respond to the diagnosis and its consequences. Therefore, it could be hypothesised that changes in personality that other people observe may in part be caused by existing personality traits, and personality changes in reaction to the challenge of dementia rather than the condition itself.

To summarise, a consensus has emerged that some personality traits change over the life course due to environmental influences. However, this is not a simple process of cause and effect. It is likely that the type and degree of

change depends on a person's innate characteristics and their ability to cope in any situations in which they find themselves.

The previous sections have focused on individuals; what types of phenomena a person remembers, how he or she feels at the time of remembering, and the characteristics that influence how a person acts, and responds to events. The following section widens the view to the society and environments in which a person exists that also affect how he or she experiences and responds to events. It provides an overview of social approaches that are most commonly drawn upon for qualitative research into the self in people with dementia, namely social constructionism and embodied selfhood.

2.2.8 Social Constructionism

The social constructionist movement developed specifically to help explain social processes such as how people describe, explain and account for the world in which they live (Gergen, 1985). This approach draws on social history, emphasising the importance of people operating together, sharing ideas and acquiring knowledge, primarily through written and verbal forms of language. Researchers taking a social constructionist stance claim that all knowledge is co-created through social, interactional processes, which means that there are multiple 'knowledges' rather than a single true reality (Willig, 2001). Different people may describe a shared event or phenomenon differently from other people who attended the same event because of the different ways they perceive and understand it. Social constructionist researchers aim to discover the various ways that reality is constructed by different people, by investigating the subjective experiences of everyday life (Andrews, 2012).

Thus the principles of social constructionism may seem to oppose the cognitive and personality based perspectives of how self is formed and maintained. Cognitive models and personality theories, whilst permitting some impact of interaction with the environment on self, reflect an individualised self that is largely determined by biology and life history, and which is predominantly stable over time. On the other hand, social constructionism offers a complementary perspective on self, which may help to fill some of the gaps in explanation and understanding within cognitive and personality theories. For example, evidence from cognitive theory suggests that self-related memories are not a consistent

factual account of a particular event because individual accounts of the same event vary. Relating this to the Self Memory System (Conway & Pleydell-Pearce, 2000) it is proposed that the working self consists of perceptual and meaning making processes that interact with memory processes to determine which self-related memories are stored and retrieved, and also impact on the meaning of them to the individual when they are retrieved. Social constructionism can add to this theory by offering an explanation as to how meanings are ascribed to memories that contribute to sense of self, because in social situations remembering is linked with wider social discourses and positions so what is remembered may result as much from the process of talking to others as it does from what an individual wants to remember about an event (Harre, 2002).

Thus, people taking a social constructionist stance aim to reveal the underlying beliefs and conventions that contribute to the ways individuals construct their realities, and the way language is used to emphasise prevailing or particular views and expectations (Cruikshank, 2012). For example, Harre (2002) proposes Positioning Theory as a development of social constructionism, stressing that the conventions of current ways of speaking and thinking can put constraints on the ways individuals think and act. Narrowing this down to considering societal views of dementia, this has become a stigmatised condition, with a diagnosis of Alzheimer's disease often viewed as a 'death sentence' (Beard & Neary, 2013). People who receive a diagnosis of Alzheimer's disease are likely to be fearful of what they will become and how society will view them (Corona & Bond, 2004). Other people are in turn likely to devalue and marginalise them, resulting in 'malignant social psychology' which is defined as the impact of poor care practices delivered by care workers that cause erosion of personhood (Kitwood & Bredin, 1992), which, combined with the loss of cognitive functions, diminishes sense of self.

A study by Orona (1990) and book by Cohen and Eisdorfer (2002) extended the view of diminishing self to one of inevitable loss of self. Orona (1990) emphasised the fear of Alzheimer's disease, implying that people would start losing their sense of self soon after being diagnosed with the disease, eventually becoming unrecognisable as the person they used to be. Orona reported interviews with relatives of people with Alzheimer's disease,

specifically asking for descriptions of incidents showing loss of identity, such as uncharacteristic behaviour. It is apparent that unusual behaviours were interpreted as meaning that a person had ceased to be the person they once were, rather than that they had changed in some way. This view was reinforced by Cohen and Eisdorfer (2002) who emphasised accounts of loss of self given by relatives of people with Alzheimer's disease, rather than highlighting the significance of small signs that aspects of a person's sense of self remained.

Other authors have taken a questioning stance, aiming to change societal views about dementia. Behuniak (2011) claimed that the social construction of people with Alzheimer's disease as 'living dead' and 'zombies' is based on dehumanisation caused by disgust and terror, fuelled by the zombie genre of popular culture. Naue and Kroll (2008) described the image of the 'demented other', caused by the prevailing view that loss of self leads to people with dementia characterising 'difference and otherness'. Similarly, Gilmour and Brannelly (2010) describe the experiences of people with dementia as 'subaltern' meaning they became a disempowered, marginalised and silenced group. All three of these articles aimed to challenge the stigma, and the stereotypical view that people with dementia no longer have a sense of self.

To conclude, Figure 2.4. summarises how a person's sense of self may be affected by being diagnosed and living with dementia, taking a social constructionist perspective.

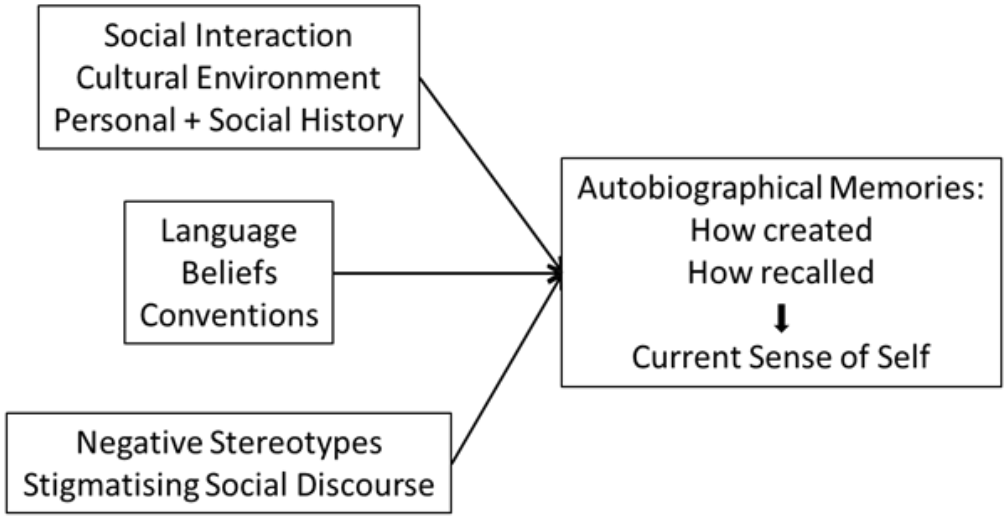


Figure 2.4: Experience of Self in Dementia

The following section moves away from the impact of wider society to consider the ways in which individuals express their selves.

2.2.9 Embodied Selfhood

As will be outlined below, a person's needs and feelings can be expressed through facial expressions and bodily movements. This relates to the theory of embodiment proposed by the twentieth century philosopher, Merleau-Ponty who claimed that his theory aided the understanding of self and identity, consciousness and communication (Carmen,1999). Merleau-Ponty postulated that embodied consciousness is a form of bodily response that does not require cognitive awareness, for example scratching an insect bite. This is a basic bodily action that the body 'knows' how to perform and does not require conscious activation; other actions can take the form of habits and skills. Merleau-Ponty argued that the body is intrinsically expressive and as such is central to the acquisition of language. He claimed that facial expressions, gestures and periods of silence should all be taken as ways of communicating the meaning of what is being said, or not said. Maine de Biran (see also section 2.2.5) analysed habits, which he observed as becoming automatic and unconscious actions with no recollection of when or how the habit was learned (Schacter,1987). Furthermore, habitual gestures and movement can indicate intentionality (Dreyfus, 2002), for example leaning towards a person indicates a desire to listen to what they are saying (Hubbard et al, 2002). Similarly, gestures and facial expressions can be seen as ways of a person expressing their feelings, wishes, and needs.

However, other researchers have proposed that autobiographical memories are associated with embodiment. For example, Bamburg (2011) linked embodiment to life stories which he claimed are the principal ways of making sense of one's self. Bamburg claimed that narration of these stories can be expressed in a variety of ways, not only verbally, such as bodily gestures, posture, facial expressions and gaze. He described two kinds of life story, namely "big stories" that consist of landmark events and "small stories" through which people construct a sense of who they are. These can be linked to the Self Memory System, with reference to general events and lifetime periods (see section 2.2.2). Merleau-Ponty claimed that performing embodied actions requires no

cognitive input, but bodily gestures that Bamburg describes can be likened to non-declarative implicit procedural memories (described in section 2.2.5).

To summarise, the previous sections have provided an indication of how the theoretical approaches chosen for this thesis provide opposing and, in some ways, complementary accounts that aid the understanding of self in dementia. The following sections report the literature review which provides further evidence to critically analyse the findings of research studies allied to the different theories and models of self.

2.3 Critical Literature Review

The purpose of this review is to set out and critique current understanding about what is known about self and dementia. Quality of studies was assessed by considering how well they were conducted, the strengths and limitations of design, participant groups and methods of enquiry. Discussion of quality is included in each section of the results.

2.3.1 Identification of Studies

An extensive literature search was conducted by the researcher in July 2013, with further searches in March 2015, February 2017 and November 2018, in order to identify studies focusing on self and dementia published from 1989 onwards. The year 1989 was chosen as a starting point because this was when the Autobiographical Memory Interview (Kopelman et al, 1989) was introduced, which has continued to provide the basis of a wealth of research into memory specifically related to the self. This also marked the beginning of wide-ranging research into Alzheimer's disease and other types of dementia, and the emergence of articles and books concerning loss of self caused by dementia.

The following electronic databases were searched: MEDLINE, ASSIA, Web of Knowledge, Web of Science, CINAHL and Psycinfo. The following search queries were used; terms related to self were: "self-concept", "self and identity", "self-awareness", "autonoetic consciousness", and "embodied self or selfhood". Terms related to memory were: "memory", "autobiographical memory", "implicit memory", and "reminiscence". Terms related to methodology were: "social constructionism", "ethology", "ethnography", "experimental", "measure", and "quantitative", plus "personality" and "personhood". All these terms were combined with "dementia" and "Alzheimer's" and filtered by "age 65 and older"

or “elderly”. In addition, seminal papers from before 1989 were identified and citing studies checked; reference sections of all relevant articles were searched, and research and citation alerts were set up for key journals (Sage Journals, Jisc Zetoc Alerts), authors (Academia.edu, ResearchGate) and key words (APA Research Alerts). Searches during 2013, 2015, 2017 and 2018 yielded 380,879 studies. New areas of research were also identified by attending conferences and workshops, e.g. “Supporting Personhood in Dementia Care, London (July 2014), Dementia and Rights Quarterly Event in Bradford, (September, 2016) and Transitions in Dementia and Social Health Public Lecture, Bradford (April, 2017). Figure 2.5 illustrates the continuous, cyclical search process, which continued throughout the course of the research study.

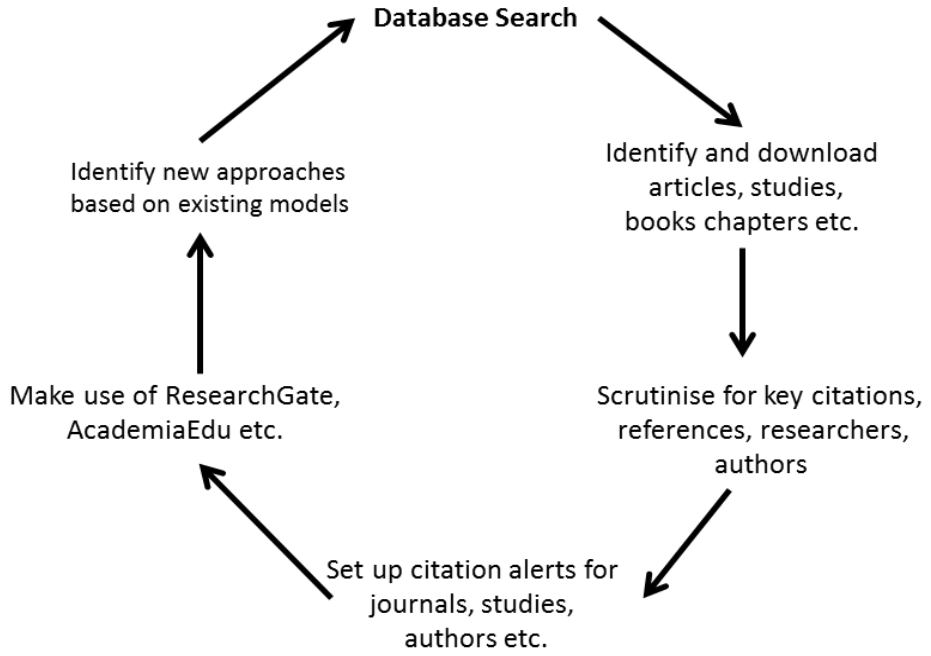


Figure 2.5 Cyclical search process

2.3.2 Inclusion and Exclusion criteria

To be included in the review studies needed to be written in English and published in peer-reviewed journals. They needed to include people with dementia as participants and make reference to specified theories of self, such as autobiographical memory systems, personality theory, and social identity theory, or theoretical approaches, including social constructionism, narrative identity, and embodied selfhood. They had to report primary research, either experimental or qualitative, or case studies; and therefore review articles were excluded. Figure 2.6 illustrates the search process.

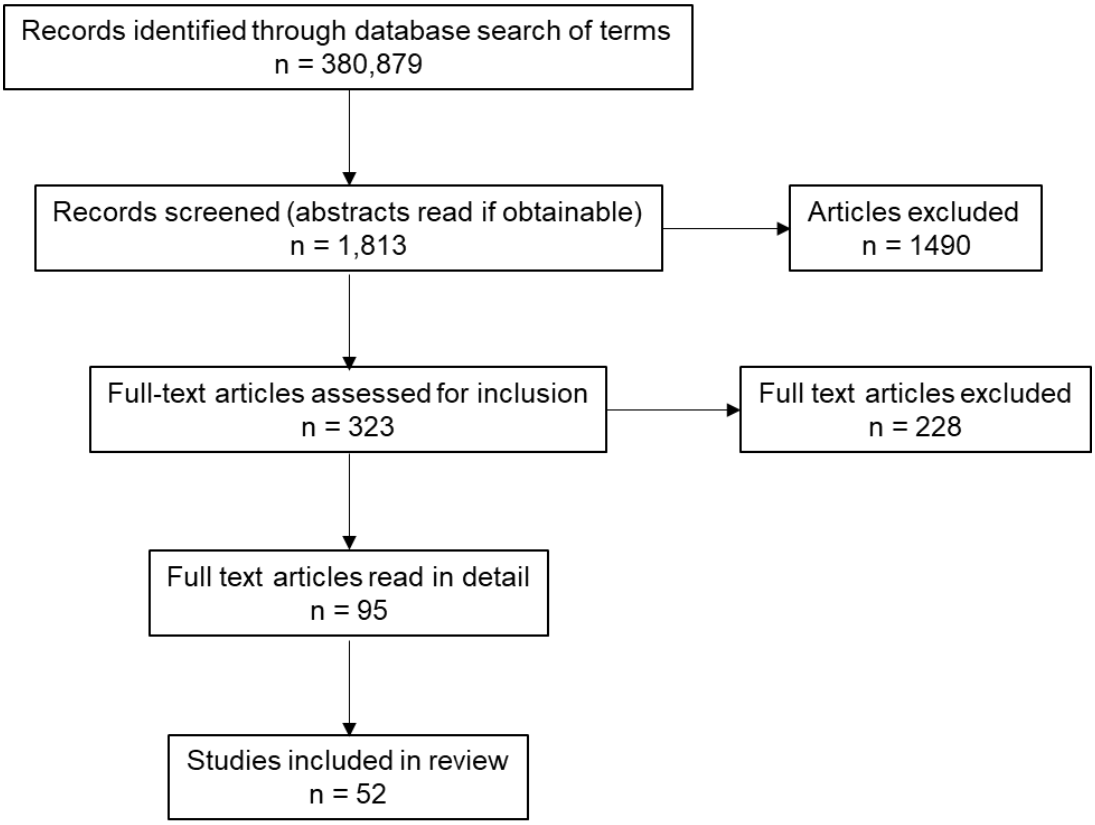


Figure 2.6 Study Identification Flow Chart

2.3.3 Results

Fifty-two studies met the inclusion criteria, of which 26 are cognitively focused, 23 socially focused (including embodied selfhood), and three studies relate to personality theory. It should be noted that the positioning of some studies was not straight forward due to the overlapping nature of underlying theories upon which they are based, so may be discussed in more than one section.

The first results based on cognitive theories focus on the impact of dementia on autobiographical memory. Examining links between this and sense of self can help in understanding how cognitive changes influence self in dementia. Later sections will focus on subjective experiences of remembering (self-awareness and self-consciousness) and how they influence sense of self and identity.

2.3.4 Autobiographical memory and self in people living with dementia

Five studies were identified that focused on the role of autobiographical memory in relation to self and identity in people with Alzheimer's disease (summarised in Table 2.1) Of these, four studies demonstrated that memory impairments in dementia were associated with change in aspects of self and identity. Firstly,

Table 2.1 Studies Investigating Autobiographical Memory, Self, and Identity in People with Dementia

Study Authors	Title	Participants	Component/s of self specified by authors	Main findings
Addis & Tippet (2004)	Memory of myself: Autobiographical memory and identity in Alzheimer's disease	20 adults with mild to moderate AD 20 age-matched controls	Identity	Participants with AD demonstrated weaker, more abstract, vague and less definite sense of identity compared with control participants.
Jetten et al (2010)	Declining Autobiographical memory and the loss of identity: Effects on well-being	15 adults with mild dementia 16 adults with severe dementia 17 age-matched controls	Identity	Loss of AM associated with weakened sense of identity.
Fargeau et al (2010)	Alzheimer's disease and impairment of self	47 adults with mild to moderate AD and their carers	3 dimensions of self: Material, spiritual, social	Majority of participants showed impairment in at least one aspect of self, most often social. Severity of impairment was correlated with severity of impairment of semantic memory.
El Haj & Antoine (2018)	Context Memory in Alzheimer's Disease: The "Who", "Where", and "When"	31 adults with mild AD and 35 age-matched controls	Contextual elements of autobiographical memory	Impairment in "who", "when" and "where" components shown by participants with AD. Most difficulty shown in remembering temporal information.
Eustache et al (2013)	Sense of identity in advanced Alzheimer's dementia: A cognitive dissociation between sameness and selfhood	16 adults with mild to severe AD 16 age-matched controls	Identity as self-consciousness and self-description.	Sense of identity broadly preserved in people with AD, although weaker than control group.

Addis and Tippet (2004) investigated the nature of autobiographical memory impairment and how this was associated with changes in identity. Twenty participants with mild to moderate Alzheimer's disease, and 20 age-matched people without dementia were asked to remember events from specific time periods (e.g. childhood, early adulthood, and recent adulthood) based on the Autobiographical Memory Interview (AMI, Kopelman et al, 1989). Identity was assessed using the Twenty Statements Test (Kuhn & McPartland,1954) and the Tennessee Self Concept Scale (Fitts & Warren, 1996). Findings showed a significant association between childhood and early adult memories and strength and quality of identity; participants with poor recall of childhood and early adult memories reported fewer specific statements and vaguer ratings of self-concept than participants without memory impairment. A later study by Jetten et al (2010) replicated Addis and Tippet's findings in a study involving 16 residents of a specialist dementia care home. Jetten et al reported that loss of autobiographical memory was associated with a weaker sense of identity, supporting the findings of Addis and Tippet. They proposed that autobiographical memory provides a foundation upon which identity is built, and so, when memory is impaired, the ability to know one's self is also impaired.

Echoing James's definition of self cited in the introductory chapter of this thesis, Fargeau et al (2010) explored changes in material, spiritual and social aspects of self associated with dementia, finding that 47 participants diagnosed with mild to moderate dementia demonstrated some degree of impairment of self. The authors suggested that severity of impairment was associated with poor semantic memory. Memory was assessed by asking participants to talk about their autobiographical memories for two minutes (episodic memory) and cite names of close friends for two minutes (semantic memory). Fargeau et al concluded that semantic memory was most impaired in participants who demonstrated impairment in all three aspects of self. Self was assessed using a scale consisting of 8 questions covering the three aspects of self. However, the scale was administered to the main carers of participants, rather than the participants themselves. It can be argued that proxy reports such as this may be biased towards the views of the carers and not truly representative of the qualities of the participants.

El Haj and Antoine (2018) also investigated the episodic memory system, specifically the contextual elements, or the “who”, “where” and “when” (p.158). They claimed that episodic recall is meaningless without these contextual elements which are important for retrieving and reliving personal incidents, and that a profound decline in episodic memory is the core symptom of Alzheimer’s disease. Thus they hypothesised that their 31 participants diagnosed with mild Alzheimer’s disease would be impaired in their abilities to recall contextual details compared with 35 adults with no memory impairment. All their participants were asked to “recount in detail” three autobiographical events relating to i) a familial event, ii) a professional event, and iii) a holiday event. They were allocated three minutes to describe each event. At the end of each account, they were asked for names of people who they were with at the event, where the event occurred, and when it occurred (e.g. the year, season, month or day). The results showed that participants with Alzheimer’s disease had impaired memory for the three contextual features compared with the control group, and that the “where” information was more impaired that “who” and “when” which the authors suggest might reflect difficulties with general timing. However, these four studies involved experimental methods that may hinder retrieval by people with dementia by asking for generative retrieval of memories.

In contrast, the fifth study by Eustache et al (2013) addressed the need to use measures designed specifically for people in the advanced stages of dementia, who have difficulty communicating. Their study investigated whether sense of identity was preserved in people with Alzheimer’s disease; their participants were 16 people in the mild to severe stages of Alzheimer’s disease and 16 age-matched adults without the disease. Using shortened versions of the tests used by Addis and Tippet (2004), Eustache et al demonstrated that sense of identity was better preserved than had been demonstrated by Addis and Tippet. They measured identity using a ten statement version of the Twenty Statements Test called the ‘I-AM test’ (Identity-Alzheimer Moderate), which required participants to complete 10 ‘I am…’ statements orally. They also used a version of the Tennessee Self Concept Scale which they called the ‘IMAGE Test’, consisting of 24 descriptive statements which participants were asked to say were true or false for them. Eustache et al administered their tests in the same format on two occasions, the second was two weeks after the first assessment, and

results remained largely consistent over this period of time. The participants with Alzheimer's disease were able to describe aspects of themselves on both occasions. Eustache et al concluded that sense of identity was broadly preserved in people with Alzheimer's disease, but they proposed that there are two aspects to sense of identity. They suggest that one aspect is relatively general and stable, and not affected by cognitive impairment; they called this the 'self-consciousness' component, or the core aspects of self, and suggest that it consists of personal feelings and an individual's ability to observe and analyse him or herself. They called the second aspect 'self-description' and suggest that this varies with time and life experiences and is therefore susceptible to be weakened by memory loss.

Thus, the study by Eustache et al introduced the possibility of investigating different aspects of self instead of the overarching concept of identity. Fargeau et al similarly considered different aspects of self, but asked for opinions of carers, rather than people with dementia themselves.

Moving on to the specificity of autobiographical memories, five studies investigated the role of episodic and semantic memories in relation to people with different types of dementia (summarised in Table 2.2). Firstly, Piolino et al (2003) carried out a study involving 13 participants diagnosed with Alzheimer's disease, 15 with the frontal variant of fronto-temporal dementia (fvFTD), 10 with semantic dementia and 18 age-matched controls with no form of dementia. All participants completed an autobiographical memory recall task that required them to describe episodic memories from 5 lifetime periods (0 to 17 years of age, 18 to 30 years, over 30 years, the most recent 5 years, and the last 12 months). The results demonstrated that the groups with dementia each differed in their profiles of autobiographical memory loss and all were slightly different from the control group. For the group with Alzheimer's disease, remote memories were better preserved than recent memories. The results were reversed for the group with semantic dementia who had more preserved recent memories, and there was no clear difference between recall and age of memories in the group with fvFTD.

Table 2.2 Studies Investigating Autobiographical Memory Loss in People with Different Types of Dementia

Study Authors	Study title	Participants	Component/s of self specified by authors	Main findings
Piolino et al (2003)	Autobiographical memory and autonoetic consciousness in neurodegenerative diseases.	13 adults with AD 10 adults with SD 15 adults with fv-FTD	Autobiographical memory + self-awareness	Participants with AD showed impaired recent memory and preserved remote memory; those with SD showed reverse profile. Participants with AD and fvFTD showed impaired autonoetic awareness.
McKinnon et al (2008)	Autobiographical Memory and Patterns of Brain Atrophy in Frontotemporal Lobar Degeneration	8 adults with FTD 9 adults with FTD/SD 16 age-matched controls	Autobiographical memory	Participants with FTD/SD most impaired in episodic memory, generated excess of semantic details. Participants with FTD showed less impaired episodic memory, and intact semantic memory.
Irish et al (2011a)	Profiles of recent autobiographical memory retrieval in semantic dementia, behavioural variant frontotemporal dementia and Alzheimer's disease	25 adults with SD 15 adults with bvFTD 17 adults with AD 16 age-matched controls	Autobiographical memory	Participants with SD showed relatively preserved recent memory compared with remote memory. Participants with AD and bvFTD showed impaired memory for all time periods.
Duval et al (2012)	What happens to personal identity when semantic knowledge degrades? A study of the self and autobiographical memory in semantic dementia.	8 adults with early to moderate SD 36 age-matched controls	Autobiographical memory and personal identity	Participants with SD demonstrated impaired semantic self-knowledge, except for present self. Identity maintained by intact episodic self-knowledge.

In a later study, McKinnon et al (2008) reported that 8 people diagnosed with frontotemporal dementia (FTD), and 9 people with mixed frontotemporal and semantic dementia (FTD/SD) were shown to have impaired episodic autobiographical recall from all time periods. Memory was assessed using the Autobiographical Interview (Levine et al, 2002). McKinnon et al suggested that self-referential processing, whereby memories related to the self are easier to recall than other memories, is fundamental for recall of episodic detail in autobiographical memories, and this capacity is impaired in people with FTD and FTD/SD. The implication is that because people with FTD and FTD/SD cannot recall episodic memories related to their past experiences, their sense of identity will also be impaired.

Irish et al (2011a) investigated memory retrieval in three groups of participants: 25 people diagnosed with semantic dementia, 15 people with behavioural-variant fronto-temporal dementia (bvFTD), and 17 people with Alzheimer's disease. Autobiographical memory was assessed by asking participants to recall memories from four lifetime periods: teenage, early adulthood, middle adulthood, and the most recent 12 months. Irish et al reported that participants with semantic dementia showed well-preserved recent memories, whereas participants with bvFTD and with Alzheimer's disease demonstrated impairment for all time periods. The authors concluded that loss of remote memories is due to a lack of semantic detail, whereas recent memories, which rely on episodic details are better preserved in people with semantic dementia. The authors also suggested that impaired performance in bvFTD is caused by multiple factors including diminished retrieval abilities and deficits in self-reflective processes associated with the disease.

Duval et al (2012) looked at how personal identity is affected when semantic knowledge is impaired and demonstrated that sense of self is well preserved, supported by intact episodic self-representations and knowledge of identity traits. Their participants were 8 people in the moderate stage of semantic dementia; personal identity was tested in terms of the strength and certainty of self-concept using a test requiring three types of response to the question "Who am I?". The answers to this question were in the form of "I am…", "I was…", and "I will be…", and the test was performed twice, once for episodic memories and once for semantic memories. Duval et al demonstrated that their participants

had intact episodic memories but were impaired in their ability to recall semantic self-images. They were also impaired in their ability to produce images of themselves in the future. However, they were able to describe current identity traits that demonstrated that they retained a strong self-concept. The authors suggest that trait self-knowledge is better preserved than other types of semantic knowledge (such as names of animals and famous people) because it is stored in areas of the brain that are not affected by semantic dementia.

These five studies demonstrated that people with different kinds of dementia had different types of memory impairment, therefore the common belief that all people with dementia have severe memory loss is incorrect. However, all the studies asked for generative retrieval by all their participants. In contrast, evidence for broadly preserved semantic memory in people with Alzheimer's disease was reported by Martinelli et al (2013). They used a different method from Addis and Tippet (2004) for generating autobiographical memories by asking their participants to describe memories that came to mind after being presented with cue-words. These were 10 common words such as family, holiday, love, and occupation. Participants were asked to recall 10 episodic memories and 10 semantic memories prompted by the cue-words. Memories were rated as episodic or semantic according to a 9-point episodic scale according to details such as context and/or any feelings (physical or mental) associated with the memory. There were three groups of participants: 18 young adults, 16 older adults with no memory impairments and 10 people with Alzheimer's disease. The participants with Alzheimer's disease demonstrated deficits in episodic memory, but their performance was equal to the two control groups for semantic recall. These results suggest that eliciting memories using cue words can make it easier for people with dementia to recall semantic memories than by simply asking for a memory from a specific time period, and using cue words associated with the self such as appearance or occupation may elicit personally significant semantic memories.

These studies also provided evidence to support Tulving's (1985) theory of distinct memory systems and evidence to suggest that they are stored in different parts of the brain. The view that semantic personal knowledge is stored in specific areas of the brain is also supported by two cognitive theories; the Memory Transformation and Systems Consolidation Theory (Wincour &

Moscovitch, 2011) and the Multiple Trace Theory (Piolino et al, 2006). These theories propose that memories that are initially formed in the hippocampus (located in the medial temporal lobe) are transformed into semantic versions that are stored in areas outside the hippocampus and the medial temporal lobe. Episodic memories remain dependent on hippocampal activation for retrieval, but retrieval of semantic memories does not involve the hippocampus. The medial temporal lobe is the area of the brain that is principally affected by Alzheimer's disease (Piolino et al, 2006), therefore memories stored in other areas of the brain may remain accessible in people with Alzheimer's disease. This provides evidence to explain the findings of Martinelli et al (2013) that access to semantic memories is preserved in people with Alzheimer's disease. Conversely, people with semantic dementia have atrophy in frontal temporal lobes, often greater in the left side of brain (Duval et al, 2012). FTD is associated with degeneration of prefrontal area (McKinnon et al, 2008) which is the area of the brain behind the forehead, some distance from the medial temporal lobes.

2.3.5 Cues and stimuli that aid memory recall

Moving on to methods of eliciting memory retrieval, five studies (summarised in Table 2.3) investigated different kinds of cues and stimuli. As described above, Martinelli et al (2013) demonstrated that in people with dementia, memories may be more easily triggered by prompts, such as cue words, than requests for generative recall of memories from specific time periods. Other studies have also produced evidence to suggest that with appropriate cueing or prompts people with dementia can be helped to access autobiographical memories. This raises the possibility of maintaining or strengthening sense of self by devising methods to facilitate access to such memories during a person's day to day activities. Cohen-Mansfield et al (2010) investigated the effectiveness of various stimuli (such as books, musical instruments, games, office equipment, needlework items) for engaging people with dementia in activities and conversation. Their participant group consisted of 193 nursing home residents who were diagnosed as having probable dementia. Participants were offered three stimuli on two separate occasions, two stimuli were representative of their past identity and one was a standard comparison stimulus. The individualised self-identity stimuli were shown to be the most effective at encouraging

meaningful activity and conversation. Thus Cohen-Mansfield et al provided evidence to show that stimuli that were meaningful to individuals because they were related to their life history were more likely than non-meaningful stimuli to engage the person. Consequently, such stimuli may trigger memories of previous roles and relationships that can help maintain a person's sense of self.

The findings of Cohen-Mansfield et al (2010) were expanded by Ilem et al (2015) who demonstrated that photographs taken before the age of 60 were more accurately recognised than current photographs by people with dementia. Their study involved 21 long-term care residents with cognitive impairment. Current photographs were taken of each participant and photographs of them as young and middle-aged adults (40 to 60 years of age) were provided by their families. Photographs were presented to each participant in groups of three; one of the participant and two of familiar people (e.g. other residents). Printed first and last names of the people shown in the photographs were also visible. Almost all the participants recognised their own name and more participants recognised their middle-aged photograph than their current photograph. Their inability to recognise their current self may be explained by a failure to update their most recent self-images. This has been explained by Souchay (2007) who suggested that people with Alzheimer's disease are impaired in their ability to update self-knowledge and because their memory is impaired, they do not realise that they have not been able to do this.

Another form of memory cueing was used by El Haj and Antoine (2017) who investigated whether retrieval of information related to the self would improve the recall of autobiographical memories in people with Alzheimer's disease. Their participants were 24 adults with probable Alzheimer's disease and a control group of 27 adults without the disease. They asked their participants to provide answers to twenty 'Who am I?" questions (re Addis & Tippet, 2004) on one occasion, followed by being instructed to "recount in detail an event in your life". They were given three minutes to describe an event. For the control condition, they were asked to read aloud a piece of general text for one minute, again followed by being asked to recall an autobiographical memory. The specificity of the memories recalled was graded on a scale of 0 to 4, with 0 representing a repeated or extended event, and 4 points representing a vivid account of a specific event. Their results demonstrated that their participants

Table 2.3 Studies Investigating Cues and Stimuli That Aid Memory Recall

Study Authors	Study title	Participants	Component/s of self specified by authors	Main findings
Martinelli et al (2013)	The Influence of Normal Aging and Alzheimer's Disease in Autobiographical Memory Highly Related to Self	10 adults with AD 10 age-matched adults without AD 18 young adults	Autobiographical memory and self	Older adults and adults with AD showed reduced episodic recall compared with young adults. All groups performed equally in recall of semantic memories. Adults with AD showed more positive and definite sense of self than other groups.
Cohen-Mansfield et al (2010)	The underlying meaning of stimuli: Impact on engagement in persons with dementia.	193 residents of a nursing home	Identity	Adults with dementia were more likely to engage with objects or tasks that are meaningful to them.
Ilem et al (2015)	Recognition of Self-Referent Stimuli in People With Dementia: Names and Pictures as Prosthetic Memory Aids.	27 adults with cognitive impairment	Self	Self-recognition was facilitated by photographs taken during early adulthood with their names printed on them.
El Haj & Antoine (2017)	Describe yourself to improve your autobiographical memory: A study in Alzheimer's disease	24 adults with probable AD 27 adults without AD	Autobiographical memory and conceptual self	Participants with AD recalled memories with more autobiographical specificity, context recall and reliving after 'I am' task than after reading general text.
El Haj et al (2018)	From Nose to Memory: The Involuntary Nature of Odour-evoked Autobiographical Memories in Alzheimer's Disease	28 adults with mild AD 30 age-matched controls	Autobiographical memory	Participants with AD showed better episodic recall (specificity, emotional experience and mental time travel) after odour exposure and music exposure than odour- and music-free condition.

with Alzheimer's disease were able to recall more detailed memories after performing the 'Who am I?' task than after reading the text. The authors suggest that performing the 'Who am I' task triggered memories that were highly related to the self, however, they did not state if the memories recalled were related to any of the 'I am' statements. In a later paper, El Haj et al (2018) tested the hypothesis that exposure to specific odour and exposure to music act as effective cues for recall of autobiographical memories in people with mild Alzheimer's disease, and may even alleviate deficits caused by the disease. Their participants were 28 adults with mild Alzheimer's disease and 30 controls without the disease. The odour stimuli were coffee and vanilla, presented separately in the form of bottles containing essential oil, the musical stimuli were a piece of classical music, and a song. The control condition was no music and no odour. Participants were instructed to recall memories using the same methods as El Haj and Antoine (2017), with the same method of scoring. The results demonstrated that the odour- and music-evoked conditions triggered memories more quickly, and with more specificity than the control condition. Because of the speed of recall of memories, the authors suggest that they are triggered spontaneously, i.e. direct rather than generative recall (see section 2.2.2).

2.3.6 The Self Memory System

Findings from studies reported above provided evidence to support the SMS. Addis and Tippet (2004), Eustache et al (2013), Fargeau et al, (2010), Irish et al, (2008), McKinnon et al (2008) and Duval et al (2012) emphasised the close relationship between autobiographical memory and self. Evidence for direct retrieval of memories was demonstrated by Martinelli et al (2013), Cohen-Mansfield et al (2010), and Ilem et al (2015), El Haj and Antoine (2017) and El Haj et al (2018) suggesting that cue words and other types of prompts and stimuli can help to elicit direct retrieval.

To summarise, the previous sections that have focused on different types of autobiographical memory and different forms of dementia have shown that:

- Episodic memory is impaired in Alzheimer's disease and that sense of self is weaker in people with Alzheimer's disease suggesting that the two of these are correlated with each other.

- However, the degree of impairment may be overestimated by the types of methods used to test this relationship which rely on lengthy questionnaires and deliberate (generative) recall.
- Cued recall or prompts can help people with quite advanced dementia engage better with material that have some connection with their past. This indicates that, at some level, personal autobiographical memories are still intact, and therefore possibly aspects of self that are related to autobiographical memory are intact also.
- Semantic memories may be less impaired than episodic, because semantic memories that are strongly related to the self are particularly well established and may be stored in areas of the brain that are less susceptible to cognitive impairment in Alzheimer's type dementia than other kinds of memory.
- Findings from people with semantic dementia have demonstrated that sense of self can be maintained by intact episodic memory, but ability to provide factual semantic knowledge about themselves is impaired.
- Findings from people with FTD demonstrated impaired episodic memory with intact semantic memory.

The following sections will focus on the phenomenological (subjective) experiences that have been shown to be associated with memory recall and other kinds of self-awareness.

2.3.7 Subjective states associated with memory recall in people with dementia

Six studies (Table 2.4) were identified that investigated recollective experience in people with Alzheimer's disease. Dalla Barba (1997), Hudon et al (2009) and Ally et al (2009) demonstrated poor performance by people with Alzheimer's disease when performing memory recall tasks. Dalla Barba (1997) investigated 'remember' and 'know' responses in two experiments that involved 12 people with Alzheimer's disease and 12 age-matched controls with no memory impairment. For the first experiment, all participants were asked to study and memorise (encode) a list of 50 words, followed by two different recognition tasks. The second experiment used 50 photographs of unfamiliar faces again followed by two recognition tasks. The first task was free recognition, in which participants were given a list of 25 words taken from the encoding list

(Experiment 1), mixed with 25 new words that were not on the original list, and a display of 25 of photographs from Experiment 2 mixed with 25 new photographs. Participants were asked to indicate the words and photographs that they recognised and state whether they 'just knew' they had seen the word or photograph before, with no memory of anything associated with seeing them, or 'remembered' seeing them, such as using a mental image or other method to help remember them. The second task was forced-choice recognition; the participants were given 25 word pairs consisting of one word from the original list of 50 words (from Experiment 1), with a new word, and 25 pairs of photographs (from Experiment 2) with unseen photographs. Participants were asked to indicate which word or photograph they recalled from each pair and again state if this recall was 'knowing' or 'remembering'. In both recognition tests, participants with Alzheimer's disease produced fewer correct responses and fewer 'remember' responses than the control group, but numbers of 'just know' responses were comparable for both groups. Dalla Barba concluded that memory performance was impaired in people with Alzheimer's disease because they had a reduced capacity to consciously recognise an item that they had previously seen. This deficit was thought to occur in the early stages of the disease, before semantic memory is affected.

Hudon et al (2009) similarly used the Remember/Know method to compare the performances of a group of 10 people with probable Alzheimer's disease with a control group of 23 age-matched adults. All participants were asked to read and memorise 30 words, followed by a recognition test consisting of the 30 original words mixed with 30 new words. The participants with Alzheimer's disease gave fewer 'remember' and 'just know' responses than the control group. The study by Ally et al (2009) reported comparable results from a study involving 10 participants with probable Alzheimer's disease and 12 age-matched controls. The participants were asked to study and remember three lists, each consisting of 80 words. These were followed by presenting a second set of lists with old and new words. Participants were asked to respond according to whether they thought words were old or new, and how certain they were of their response. Results again demonstrated that participants with Alzheimer's disease were impaired in their abilities to both 'remember' and 'just know' the accuracy of

Table 2.4 Studies Investigating Recollective Experience in People with Dementia and Mild Cognitive Impairment

Study Authors	Study title	Participants	Component/s of self specified by authors	Main findings
Dalla Barba (1997)	Recognition Memory and Recollective Experience in Alzheimer's Disease	12 adults with AD 12 age-matched controls	Conscious awareness: remembering and knowing	Participants with AD made more errors than controls and gave fewer 'remember' responses. Numbers of 'know' responses were comparable between both groups.
Hudon et al (2009)	The assessment of recognition memory using the Remember/Know procedure in amnestic mild cognitive impairment and probable Alzheimer's disease.	20 adults with MCI 10 adults with AD 23 age-matched controls	Conscious awareness: remembering and knowing	Participants with MCI showed impaired 'remember' responses and 'know' responses were comparable to the control group. Participants with AD showed impairment in both types of response.
Ally et al (2009)	An evaluation of recollection and familiarity in Alzheimer's disease and mild cognitive impairment using receiver operating characteristics.	11 adults with MCI 10 adults with AD 12 age-matched controls	Conscious awareness: remembering and knowing	Participants with MCI and AD showed impairments in both 'remembering' and 'knowing' compared with the control group.
Irish et al (2011b)	Impaired capacity for autonoetic reliving during autobiographical event recall in mild Alzheimer's disease. Autobiographical memory	20 adults with mild AD 30 older adults without dementia 30 middle-aged adults	Autobiographical memory and autonoetic consciousness	Participants with AD had impaired episodic memory compared with other groups. Recall of events was fragmented and depersonalised.

Piolino et al (2003)	and autonoetic consciousness in neurodegenerative diseases.	13 adults with AD 10 adults with SD 15 adults with fv-FTD	Autobiographical memory and self-awareness	Participants with AD showed impaired recent memory and preserved remote memory; those with SD showed reverse profile. Participants with AD and fvFTD showed impaired autonoetic awareness.
Tippet et al (2018)	The Persistence of the Self over Time in Mild Cognitive Impairment and Alzheimer's Disease	15 adults with AD 15 adults with MCI 25 adults with no cognitive impairment	Persistence of self over time and autobiographical memory	Participants with AD showed impaired episodic memory but sufficient features from semantic memory to sustain feelings of self-continuity.

Key: AD = Alzheimer's disease, SD = semantic dementia, fv-FTD = frontal-variant fronto-temporal dementia, MCI = mild cognitive impairment.

their replies. Thus, the results of Hudon et al and Ally et al disagree to some extent with those of Dalla Barba (1997).

Three studies specifically investigated autonoetic consciousness in people with Alzheimer's disease, and in people with fronto-temporal dementia. A study by Piolino et al (2003, also described in section 2.4.4 and Table 2.2) demonstrated that people with Alzheimer's disease and people with fvFTD experience a deficit of autonoetic consciousness. Their study involved 38 participants with Alzheimer's disease, fvFTD or semantic dementia and a group of 18 adult controls. All participants completed an autobiographical memory recall task that required them to describe episodic memories from 5 lifetime periods. Participants were also asked to make 'remember' or 'just know' judgements for each memory recalled. Participants with Alzheimer's disease and fvFTD reported fewer remember responses than the control group, demonstrating impaired autonoetic consciousness.

Irish et al (2011b) also demonstrated impaired autonoetic 'reliving' in participants with Alzheimer's disease. Their participants were 20 people with mild Alzheimer's disease, and two control groups of 30 middle-aged and 30 older adults. Participants were asked to recall memories from five lifetime periods comparable to Piolino et al (2003), but instead of asking for 'remember' and 'just know' judgements, Irish et al asked questions about the vividness of imagery and whether there were emotions associated with the memories. The results demonstrated that the participants with Alzheimer's disease had impaired autonoetic consciousness causing them to recall autobiographical events as fragmented, depersonalised semantic accounts of what had once been evocative events.

More recently, Tippet et al (2018) reported a study that incorporated several autobiographical memory related theories and models, i.e. episodic and semantic memory, autonoetic consciousness, the reminiscence bump, and the Self Memory System. The authors proposed that the process of remembering the self during episodic recall supports the belief that a person has of being the same person across his or her lifespan; they call this belief 'diachronic unity'. They propose that diachronic unity is supported by i) autonoetic consciousness that is experienced through episodic recall and ii) subjective beliefs about the self that are known via semantic memory. They suggest that if episodic memory

is impaired by Alzheimer's disease or mild cognitive impairment, diachronic unity remains intact if it can be supported by semantic memory. They investigated this hypothesis in their study that involved 15 adults with Alzheimer's disease, 15 adults with mild cognitive impairment, and a control group of 25 adults with no memory impairment. They performed interviews with all their participants in order to examine whether they still believed they were the same person as in their early 20s, and how well they could recount their life story, divided into four 'chapters' (0 to14 years, 15 to 25 years, 26 to 50 years, and 51 years to present; the 15 to 25-year period was intended to isolate the reminiscence bump). These accounts required generative retrieval, with participants being asked to talk about the most important events in their life, and the biggest changes that had happened to them. The interviews were transcribed, coded and scored for self-persistence, global coherence (combined temporal, causal and thematic elements of the life story) and cultural life script events (equivalent to lifetime periods of the SMS, section 2.2.2). Their results demonstrated that the life stories of participants with mild cognitive impairment were comparable to those of the control group, whereas the life stories of the group with dementia were less coherent, especially with regard to chronology of events. However, the reminiscence bump time period showed the greatest coherence for all groups. Furthermore, the life stories of the group with Alzheimer's disease retained features of cultural life script events that appeared to be sufficient to sustain strong beliefs about self-continuity. Thus, the authors concluded that semantic memories may enhance a person's capacity to understand and explain their experience of being the same person over their lifetime.

To summarise, all these studies were investigating cognitive deficits and demonstrated impaired episodic memory in people with dementia and Alzheimer's disease, and the associated sensory experiences that accompanied them. These findings can be explained with reference to the Self Memory System. Conway and Pleydell-Pearce (2000) proposed that a defining feature of episodic memories is that they contain 'event specific knowledge' which relates to the vividness of memories, and to autonoetic consciousness. Episodic memories are easily lost because they are outside the autobiographical knowledge base and therefore event specific knowledge can

similarly be lost. However, in all the studies researchers used experimental methods that were cognitively demanding so impairments may have been exaggerated, but, as results of the final study by Tippet et al (2018) suggest, sense of self may continue to be supported by semantic memories, particularly memories of events that occurred during the reminiscence bump period.

The next section moves from subjective experience of remembering to the subjective awareness of the self, both cognitive and physical.

2.3.8 Studies investigating self-awareness in people living with dementia

Six studies were identified for this section (summarised in Table 2.5). Firstly, self-awareness was investigated by Gil et al (2001) involving 45 participants who had been diagnosed with mild and moderate Alzheimer's disease. The researchers conceptualised self-awareness as multifaceted, including awareness of one's body and physical position, one's perceptions (sight, sound etc.), cognitive abilities, life history, continued identity, past and present projects, and one's moral stance. Their measurement tool was a questionnaire consisting of 14 questions relating to the multiple aspects of self-awareness. Their results demonstrated that awareness of cognitive deficits and ability to imagine the future were affected more severely than awareness of identity and body posture. The researchers concluded that Alzheimer's disease affected self-awareness differentially rather than causing total loss of awareness.

Regarding awareness of cognitive function, three studies were identified that specifically investigated reduced awareness of memory deficits and whether this affected sense of identity. Naylor and Clare (2008) studied 30 people with various forms of dementia in the early stages of the condition. They used measures of autobiographical memory, self-concept and awareness of memory functioning. Their results demonstrated that reduced awareness of memory functioning was associated with a more positive and definite identity, thus Naylor and Clare suggested that reduced awareness of cognitive function may have a protective role against possible perceived threats to self as a result of being diagnosed with dementia.

Morris et al (2014) also investigated awareness of memory dysfunction in 46 people with Alzheimer's disease and 30 people with vascular dementia (both at mild stages of the conditions) compared with a control group of age-matched

Table 2.5 Studies Investigating Self-awareness in People with Dementia

Study Authors	Study title	Participants	Component/s of self specified by authors	Main findings
Gil et al (2001)	Self-consciousness and Alzheimer's Disease.	18 adults with mild AD 27 adults with moderate AD	Multifaceted self-awareness and identity	Awareness of cognitive deficits such as imagining the future and moral judgements were more severely impaired than sense of identity. No difference between groups.
Naylor & Clare (2008)	Awareness of memory functioning, autobiographical memory and identity in early-stage dementia	30 adults with early stage dementia	Autobiographical memory and identity	Participants showed reduced awareness of memory function associated with poor recall of midlife memories; also demonstrated more positive and definite sense of identity.
Morris et al (2014)	Awareness of memory task impairment versus everyday memory difficulties in dementia.	46 adults with AD 30 adults with VaD 76 carers with no cognitive impairments	Self-awareness	Participants with AD and VaD showed significantly less awareness of everyday memory impairment than carers group.
Clare et al (2008)	'I don't do it like I used to do': A grounded theory approach to conceptualising awareness in people with moderate to severe dementia living in long-term care.	80 adults living with dementia in care homes	Self-awareness and sense of self	All participants demonstrated some aspects of awareness in relation to self, relationships, and environment.
Markova et al (2014)	Phenomena of awareness in dementia: Heterogeneity and its Implications.	101 adults with early stage dementia	Multi-faceted self-awareness described as 'objects'	Differences in patterns of awareness depending on 'object' of awareness: memory, functional, activity, socio-emotional.

Simm et al (2017)	Making sense of self in Alzheimer's disease: reflective function and memory	49 adults with early-stage AD 26 adults without dementia	Capacity for self-reflection and memory	People with AD have impaired capacity to understand their thoughts, feelings and beliefs, and interactions with other people.

adults with no cognitive impairment. Results showed that people in the dementia group had significantly lower levels of awareness of memory functioning than the control group. The researchers concluded that loss of awareness can occur without substantial cognitive impairment, also suggesting a protective function of denying that a problem exists at a stage before more severe and obvious impairments become apparent.

Simm et al (2017) propose that impaired self-awareness in people with Alzheimer's disease may result from deficits in their new-learning abilities, which affect their capacity for understanding their internal thoughts, feelings and beliefs. Simm et al investigated the effect of personal and social reflective capacity on sense of self in people with mild dementia related to Alzheimer's disease. They described the capacity for personal and social reflection as a process that is necessary for maintaining a sense of self, the ability to understand one's personal mental world, and for understanding the social world and interactions with other people. This capacity was measured by a modified version of the 'Reflective Self-Function Scale' (Fonagy et al,1991), that consisted of a flexible number of open-ended questions concerning activities and social interactions that participants had recently experienced. New-learning ability was measured by the recall of the 'Word List' subset of the Wechsler Memory Scale (Wechsler, 1997). The study participants were 49 adults with early stage dementia associated with Alzheimer's disease and a control group of 26 adults without dementia. Their results demonstrated that the group with dementia had impaired personal and social reflective capacity compared with the control group, and that this impairment correlated with their new-learning ability. The authors suggest that people with dementia have a reduced capacity to understand and reflect on their thoughts, feelings and beliefs about themselves, i.e. to be self-aware.

However, as previously stated, the experimental studies that used cognitive measures of self-concept, self-awareness and cognitive abilities, may overestimate impairment in people with dementia. Qualitative studies have also investigated self-awareness, for example Clare et al (2008) investigated how different levels of awareness were manifested in people with dementia, and the results demonstrated that retained awareness outweighed unawareness, which

contradict the findings from cognitive studies of loss of awareness. Clare et al used grounded theory analysis of conversations with 80 people with moderate to severe dementia living in residential care homes. All participants were reported as demonstrating retained awareness in relation to sense of self, personal relationships and their environment. Thus some retained self-awareness was demonstrated when multiple aspects of awareness were considered.

Markova et al (2014) emphasised the diversity of explanations for impaired awareness by describing it as a cognitive symptom of the dementia process, along with impaired awareness caused by the reaction of an individual to changing socio-cultural factors. They reported an approach that investigated three 'objects' of awareness, i.e. memory functioning, functional activities and socio-economic functioning. They used three different measures in their study that focused on each of these types of awareness, namely the Memory Awareness Rating Scale (MARS, Clare et al,2002), the Functional Activities Questionnaire (Pfeffer et al, 1982) and the Socio-Emotional Questionnaire (Bramham et al, 2009). Their participants were 101 people diagnosed with early stage Alzheimer's disease, vascular dementia, or mixed Alzheimer's and vascular dementia. The same questionnaires were administered to relatives or carers of these participants and results were compared to determine discrepancy scores. Their results demonstrated that the views of participants did not always coincide with those of their relatives and carers, according to the object of awareness. The most significant discrepancies occurred in relation to socio-emotional awareness. Markova at al suggested that this occurred because appraising one's self when one is interacting with others is more complex than rating one's memory and functional abilities. This again highlights the need to not view awareness as a single phenomenon, instead it should be considered in relation to the 'object' of awareness (i.e. memory, functional abilities or social interaction).

Thus, focusing on multiple aspects of self-awareness has demonstrated that it is possible to combine cognitive experimental research approaches with qualitative data to provide a fuller picture of the abilities of people with dementia.

The next section focuses on personality theories demonstrating that personality is a component of self that can affect how a person with dementia visualises him or herself, and how he or she presents him or herself to others.

2.4 How does dementia affect a person's personality?

Three studies were identified that focused on change in personality in people with dementia (Table 2.6). All three studies suggested that personality change occurs in people with dementia, and the authors reported negative changes. For example, Talassi et al (2006) asked the caregivers of 52 people diagnosed with Alzheimer's disease to rate changes of personality in the people they cared for. Talassi et al reported that the changes carers perceived included reductions in sociability, happiness, enthusiasm and kindness. Likewise, Aitken et al (1999) asked relatives of people diagnosed with dementia about their relatives' personality before and after the onset of the condition. Relatives reported personality changes associated with apathy, irritability, passivity and agitation with these increasing as dementia progressed. However, in contrast to Talassi et al (2006), Aitken et al (1999) found that relatives reported that some positive personality traits were retained including kindness, affection, fondness for company and generosity.

However, there are a number of limitations to these studies in terms of their contribution to understanding of personality and sense of self in people with dementia. Firstly, both studies (Talassi et al; Aitken et al) used proxy (caregiver) reports of personality, with Talassi et al rejecting self-report as a method, claiming that self-reports by people diagnosed with dementia cannot be considered reliable because of impaired insight, judgement and memory. There is merit in the argument as to why people such as a carer, who have known a person with dementia for many years may be considered better able to describe personality change than the person themselves, particularly in light of studies already discussed in this chapter which indicate that awareness may be reduced in people with the condition. However, there is a wide body of evidence that indicates that self and proxy reports of personality to not correlate well, even in the general population; i.e. others do not see us as we see ourselves. In view of this, Clare et al (2002) question the use and reliability of carer, or other informant, ratings suggesting they may be biased by variables such as the quality of relationship, personality and quality of life of the carer. A study by

Table 2.6 Studies Investigating Personality in People with Dementia

Study Authors	Study title	Participants	Component/s of self specified by authors	Main findings
Talassi et al (2006)	Personality changes in Alzheimer's disease.	Proxy ratings by carers of 52 adults with AD	Personality traits	Evidence for personality change in adults with AD, mostly perceived as negative by carers. More pronounced change with advancing cognitive decline.
Aitken et al (1999)	Personality Change in Dementia	Proxy ratings from carers of 99 adults with AD and other forms of dementia	Personality traits	Evidence for change in personality, mostly described as negative, associated with severity of condition.
Ruby et al (2009)	Perspective taking to assess self-personality. What's modified in A.D.?	14 adults with mild dementia, and their relatives 17 age-matched controls	Personality traits	Participants with AD showed impaired judgements of their own traits compared with the opinions of their relatives.

Ruby et al (2009) supports the use of self-report and suggests that in the early stages of dementia at least, people are able to assess their own personality traits and characteristics. Using a personality questionnaire that they had devised specifically for people diagnosed with mild Alzheimer's disease and their relatives (spouses or children), they found that there were no significant differences between participants' and relatives' assessments. They concluded though, that some minor differences between the ratings indicated that the ability of people with Alzheimer's disease to assess their own personality traits was impaired to some degree, signifying that despite their intentions to promote the use of self-report, the proxy report was still considered to be more accurate than self-report.

The second critique of existing studies on personality change in dementia is their reliance on observable behaviours such as irritability, agitation, apathy and passivity as indicators of change in underlying personality traits. These behaviours feature in clinical assessment and descriptions of dementia where they are often given labels such as 'challenging behaviours' (Todd & Watts, 2005), 'behavioural and psychological symptoms of dementia' (Purandare et al, 2000), and 'neuropsychiatric symptoms' (Livingstone et al, 2005). Evidence from clinical practice (e.g., Lyketsos, 2007; Gauthier et al, 2010) suggests that despite the labels given to these behaviours, many are not a direct result of the dementia disease process but are reactions to the fear and confusion caused by having dementia and exacerbated by unhelpful or unsupportive care practices. This therefore suggests that studies reliant on observation of behaviours by proxy as an indicator of underlying personality change may not in fact be measuring personality and thus cast doubt on the validity of such studies.

The following section introduces socially focused theories and approaches to the study of self in dementia. It also illustrates overlapping views about personality, self and identity.

2.5 Social approaches to the study of self in people with dementia

The approaches that are most commonly drawn upon for qualitative research into the self in people with dementia are based on social constructionism and embodied selfhood. Studies based on these two approaches will be discussed and critiqued in the following sections. Twenty-one studies, mostly taking a

social constructionist approach, investigated the lived experiences of people with dementia. Seven studies were identified as investigative or exploratory (summarised in Table 2.7) and 14 provided evidence to support the persistence of self in people diagnosed with dementia (summarised in Tables 2.8. and 2.9).

2.5.1 Exploratory studies of the lived experience of people with dementia

Each of the exploratory studies had the overall aim of investigating what it is like to live with dementia by asking for the views of the people who experience it. Holst and Hallberg (2003) explored the meaning of everyday life in 11 people diagnosed with dementia. The researchers used a biographical method, asking participants to talk about events that had special meaning for them. Their findings demonstrated that many of their participants felt shame, sorrow and sadness after being diagnosed with the disease, but were able to look ahead to a more manageable life and so expected to be able to maintain their sense of self. Graneheim and Jansson (2006) painted a less positive picture given to them by three people diagnosed with dementia living in a residential home. They carried out a series of informal interviews and reported that their participants experienced poor maintenance of self, mainly due to a collapse of relationships between the people they interviewed and the people who cared for them. Granheim and Jansson concluded that nursing care was dependent on the view the carers had of their residents, and if care was poor, ‘disturbing behaviours’ such as aggression, screaming, and wandering may have been the only way a resident could communicate and try to maintain their sense of self.

Steeman et al (2007; 2013) also portrayed living with dementia as a struggle to maintain feelings of being valued. Steeman et al (2007) used grounded theory methodology, interviewing 20 people diagnosed with mild dementia and their families. They concluded that being valued was a central concern; they felt that dementia posed a threat because of reactions from other people. Steeman et al (2013) conducted a follow up study, interviewing 17 of their original participants. They reported that maintaining a sense of self had become the main concern, due to the losses caused by dementia, such as loss of independence, self-esteem and the sense of no longer being valued by others. However, participants’ accounts suggested that it was still possible to maintain a sense of

Table 2.7 Studies Exploring the Self-reported Lived Experiences of People with Dementia

Study Authors	Study title	Participants	Component/s of self specified by authors	Main findings
Holst & Hallberg (2003)	Exploring the meaning of everyday life, for those suffering from dementia	11 adults with mild to moderate AD	Sense of self	Participants expressed feelings of shame, sadness and sorrow, but also indicated feelings of hope that they would be able to adjust to living with the disease and maintain their sense of self.
Graneheim & Jansson (2006)	The meaning of living with dementia and disturbing behaviour as narrated by three persons admitted to a residential home.	2 adults with AD 1 adult with VaD	Personal self and social self	Participants reported poor maintenance of self because of lack of support from other people, and feeling trapped and restricted in their home.
Steeman et al (2007)	Living with dementia from the perspective of older people: Is it a positive story?	20 adults with mild dementia and their family members	Identity	The need to feel valued was most important to the participants, rather than loss of cognition or identity.
Steeman et al (2013)	Managing identity in early-stage dementia: Maintaining a sense of being valued.	17 adults with early stage dementia	Sense of self	Participants reported their main concern to be maintaining their sense of self, they described a shift from being valued for 'what you do' to 'who you are'; but self can be maintained by adjusting to losses caused by dementia.
Tranvag et al (2014)	Crucial dimensions constituting dignity experience in persons living with dementia.	11 adults with AD 1 adult with MCI	Self and life stories	Evidence found for persistence of self by participants recounting their life stories and recognising their own values.

Harris & Keady (2009)	Selfhood in younger onset dementia: Transitions and testimonies	23 adults diagnosed with younger onset dementia	Selfhood and identity	Participants expressed desires to maintain family and social roles that they felt were integral to their identities.
O'Sullivan et al (2014)	Action research: Changing history for people living with dementia in New Zealand.	11 adults with mild to moderate dementia and their carers	Self-respect	Participants expressed their desires to continue living positively with dementia whilst having to endure negative societal attitudes

self by finding value in the person they had become. Tranvag et al (2014) focused on maintaining dignity, which they defined as an inherent and sacrosanct quality of every human being. They conducted qualitative interviews with 11 people diagnosed with Alzheimer's disease, and identified several aspects of dignity that could be maintained whilst living with dementia, including acknowledging one's life history, recognising one's human worth, living according to internal values and being part of a caring community.

Harris and Keady (2009) explored the meaning and construction of self in people with young onset dementia (any form of dementia in which symptoms started before the age of 65). They conducted interviews with 23 people diagnosed with younger onset dementia, and reported that their participants wanted to maintain existing social and family roles which they felt were integral aspects of their self. Finally, O'Sullivan et al (2014) highlighted that there continued to be a need for attitudinal change of view away from the dominant negative discourse of loss of all mental capacities and people with dementia being an increasing burden to their carers. O'Sullivan et al interviewed 11 people diagnosed with mild to moderate dementia and their carers, who expressed their desire to continue living positively with dementia, whilst still enduring negative societal attitudes.

Overall, these seven studies emphasised the desire of people with dementia to maintain a sense of self, knowing that this requires the support of other people. A number of the studies also emphasised how difficult this can be in the face of society's negative images of dementia, which were reported as damaging people's sense of worth, as described in section 2.2.8.

2.5.2 Studies demonstrating the preservation of self in dementia

The following 11 studies (Table 2.8) provide evidence that a sense of self can be preserved in dementia. Sabat and Harre (1992, 2002, 2005) have consistently promoted the view that some aspects of self can be preserved in people with dementia. They developed a framework of self, based on social constructionism, that other researchers have used as a basis for further studies. Sabat and Harre (1992) started by proposing that self does not require a fully intact memory, and therefore Alzheimer's disease need not lead inevitably to a complete loss of self. They presented two case studies to support their claim

Table 2.8 Studies Investigating Persistence of Self in People with Dementia

Study Authors	Study title	Participants	Component/s of self	Main findings
Sabat & Harre (1992)	The Construction and Deconstruction of Self in Alzheimer's Disease	2 adults with AD	Self 1: personal self Self 2: personae presented to others	Self 1 remained intact despite impaired cognitive function. Self 2 remained intact to some degree into later stages of AD.
Sabat (2002)	Surviving manifestations of selfhood in Alzheimer's disease	1 adult with moderate to severe dementia	Selves 1 and 2 Self 3: personae created with support from others	Evidence to suggest that aspects of all 3 selves remained to some degree.
Sabat (2005)	Capacity for Decision-Making in Alzheimer's disease: Selfhood, Positioning and Semiotic People	1 adult with probable AD	Selves 1, 2 and 3	Selves 1 and 2 intact. Self 3 vulnerable if others focus on dysfunctional aspects of Self 2 caused by AD.
Small et al (1998)	The discourse of self in dementia	17 adults with dementia	Selves 1 and 2	Participants displayed evidence of retained selves verbally and non-verbally.
Tappen et al (1999)	Persistence of Self in Advanced Alzheimer's Disease.	23 adults with mid to late stage AD	Sense of self and personal identity	Participants displayed evidence of retained self by frequent use of first person indexical.
Mayhew et al (2001)	Communication from Individuals with Advanced DAT: Can it Provide Clues to Their Sense of Self-Awareness and Well-Being?	15 adults with mild to severe dementia	Self	Participants showed awareness of cognitive deficits and continued to express sense of self by using personal pronouns and expressions of humour.

that self and identity can continue even if memory is impaired. Stressing the linguistic principles that underlie social constructionism they suggested that the use of first person pronouns (I, me, myself, mine) confirm the continued existence of self and identity; they called this ‘Self 1’. Their case studies were two people who had been living with Alzheimer’s disease for approximately four years who attended a day centre. One participant was able to communicate verbally, the other by using gestures. Both showed evidence for the existence of Self 1, either by frequent use of I, me and my (first participant) or pointing gestures, such as indicating a desire to sit in her own chair (second participant). Sabat and Harre also identified Self 2 which they defined as personae that are presented to others, and that require the cooperation of others. Both participants displayed evidence that the personae presented as Self 2 were being lost. The first participant was not able to express his academic past whilst he was at the day centre, and so was unable to feel the status that he used to have. Conversely, the second participant was able to express the helpful and caring aspect of herself by helping to serve meals and looking after other residents, but whilst at home, her husband perceived her as requiring help with all her activities. Because he thought she could no longer perform housework or care for herself her husband regarded her as confused and helpless. Sabat and Harre use this as evidence to demonstrate that when a person is diagnosed with dementia, behaviours suggesting confusion and misunderstanding can be interpreted as symptoms of cognitive impairment, rather than lack of sensitivity and patience of the people around them.

In later papers, Sabat (2002, 2005) revised the model to include three selves by extending the initial conceptualisation of Self 2:

- Self 1: the personal identity that underlies the publicly presented personae
- Self 2: a person’s past and present mental and physical attributes.
- Self 3: the multiple personae that are constructed with the help and cooperation of others.

Self 1 is considered relatively robust and resistant to change, but Sabat (2002) emphasised the need for other people to provide continuing recognition and support for Selves 2 and 3. With reference to the two case studies above, the first participant could be seen as not receiving support for his Self 2 at the day

centre; the second participant was receiving support for Self 2 and 3 at the day centre, but not from her husband.

Also taking a social constructionist stance, Small et al (1998) used Sabat and Harre's (1992) model of self as a basis for analysing language and non-verbal behaviours demonstrating retained aspects of self in people diagnosed with dementia. Their detailed analysis of interactions between 17 residents of a care home and members of staff demonstrated that Self 1 and Self 2 could be revealed by a variety of verbal and non-verbal behaviours, and there was evidence to show that people who could not express themselves verbally were still conscious of their own desires and rights. For example, if they refused to sit down it was because they were exerting their right to choose between sitting in the room and standing. Small et al concluded that self can be manifested in varied ways, and be shown to be resilient to cognitive impairment.

Sabat and Harre's first model of self inspired research by Tappen et al (1999) who demonstrated persistence of self in 23 people diagnosed with middle to late stage Alzheimer's disease. Their participants used first person indexicals and showed awareness of their cognitive impairments. Similarly, Mayhew et al (2001) reported that 15 people with advanced dementia were aware of their cognitive decline, continued to used personal pronouns, and could express pleasure and humour by smiling and laughing.

2.5.3 Support for self with help from other people

Eight studies focused on how self could be supported by others (summarised in Table 2.9). Kelly (2010) observed 14 people diagnosed with dementia who were staying in hospital old age mental health wards, and collected evidence to demonstrate that Selves 1, 2 and 3 could be supported by occupational therapy staff who were trained to recognise all levels of self. However, ward staff who were trained in observing the physical condition of individuals generally only supported Self 1. Smebye and Kirkevold (2013) also investigated the value of relationships for 10 people diagnosed with dementia and reported that the relationships that were most likely to support the self were family carers and professional caregivers with whom they had close emotional bonds. Relationships that diminished personhood were those characterised by carers

who were task-oriented and reluctant to help in other ways. Similarly, Hedman et al (2012) used semi-structured interviews, based on Sabat and Harre's model, to determine how 12 people diagnosed with Alzheimer's disease expressed their sense of self. Results showed that Self 1 was expressed verbally by the use of first person indexicals and Self 2 was displayed with minor changes which were seen as positive because they included new skills that helped the person manage life with AD. Self 3 was supported to some extent by sympathetic carers, thus, overall people perceived themselves as still basically the same as before they were diagnosed with Alzheimer's disease.

Beard and Fox (2008) interviewed 40 people diagnosed with Alzheimer's disease who attended support groups. They found that being a member of a support group helped to provide a new sense of identity aided by other members of the group and by incorporating the 'label' of 'a person with Alzheimer's disease' into their new identity. This could be seen as relating to Sabat's Self 2, in that it is concerned with the sense of one's personal attributes and characteristics, showing that this was updated and maintained through the process of meeting with others with dementia.

Eight women diagnosed with dementia who were living on their own were studied by Frazer et al (2012) who demonstrated that these women were able to maintain their identities in spite of having the condition. Their interviews covered themes such as the impact of memory impairment on maintaining their independence, past and present views of themselves, relationships with others and coping strategies. The authors analysed their findings with reference to Sabat 's Three Selves model and reported a desire amongst all their participants to maintain Self 2 by using a variety of coping strategies, such as staying creative by participating in previous hobbies and leisure activities, and actively maintaining relationships with neighbours, friends and attending social clubs. The women were able to accept lost aspects of their previous selves and adapt to their changing sense of self. A similar theme of coping strategies was investigated by Pearce et al (2002), but their participants were 20 men who had been diagnosed with dementia, and their wives. They were interviewed as couples and the authors reported that coping comprised an on-going combined process of maintaining, reappraising and reconstructing their selves and

Table 2.9 Studies Investigating Persistence of Self with Support from Others

Study Authors	Study title	Participants	Component/s of self specified by authors	Main findings
Kelly (2010)	Recognising and supporting self in dementia: a new way to facilitate a person-centred approach to dementia care.	14 adults with mild to severe dementia living in hospital setting.	Selves 1, 2 and 3	Participants' interaction with staff was limited on wards so little support for Selves 2 and 3. Activity sessions provided more interaction giving support for all selves.
Smeybe & Kirkevold (2013)	The influence of relationships on personhood in dementia care: a qualitative, hermeneutic study.	10 adults with dementia each with a family carer and professional carer	Self and personhood	Relationships that sustained self were those with a close emotional bond (family) and good professional carers. Relationships that reduced personhood were task-centred only.
Hedman et al (2012)	How people with Alzheimer's disease express their sense of self: Analysis using Rom Harre's theory of selfhood.	12 adults with mild to moderate dementia	Selves 1, 2 and 3	Participants demonstrated preserved Self 1, minor changes to Self 2. Self 3 was supported by others to some extent.
Beard & Fox (2008)	Resisting social disenfranchisement: Negotiating collective identities and everyday life with memory loss.	40 adults with MCI or early onset AD	Collective identity	Social disenfranchisement leads to re-negotiation of interactions with others and personal identities that need to be incorporated into new self-identity.
	How older women who live	8 adults (all women)		Participants described coping strategies

Frazer et al (2012)	alone with dementia make sense of their experiences: An interpretative phenomenological analysis.	with AD or mixed dementias	Selves 2 and 3	and support needed from others to help maintain Selves 2 and 3.
Pearce et al (2002)	Managing sense of self. Coping in the early stages of Alzheimer's disease.	20 adults (all men) with early stage AD	Sense of self and identity	Participants attempted to manage sense of self by balancing wish to maintain previous selves with need to construct new selves.
Surr (2006)	Preservation of self in people with dementia living in residential care: A socio-biographical approach.	14 adults with dementia	Self	Participants demonstrated evidence of retained self via relationships with family and other residents, by adopting social roles and by telling stories.
Cohen-Mansfield et al (2000)	Self-identity in older persons suffering from dementia: preliminary results.	38 adults with dementia, and carers and family members	Self-identity via different role identities. Sense of self	Most role identities deteriorated but some were preserved, notably family role. Evidence for preserved sense of self even in later stages

identities. Often this consisted of downgrading and adapting to less preferred identities as their abilities changed, but their selves continued to be maintained through the continuation of previous roles where possible, and the creation of new roles through new relationships.

The relevance of a sociobiographical theory of self was investigated by Surr (2006) who integrated interpersonal relationships, social context and the life stories of 14 people living with dementia in residential care homes. Surr reported that social relationships with family and care staff were important for maintenance of self. Biographical details such as social roles related to occupations, and caring for others were particularly important, and being able to talk with others about life events. The participants continued to generate life stories, despite having memory impairments, and position their present experiences in relation to their past lives in order to maintain their sense of self.

Concentrating on social aspects of self, Cohen-Mansfield et al (2000) used a 'Self-Identity in Dementia' questionnaire, looking specifically at Self 3, which they divided into four types of social identity:

- Professional
- Family
- Leisure activities
- Personal attributes related to group membership

Participants were 38 residents of a nursing home who had been diagnosed with various forms of dementia. Cohen-Mansfield et al took the view that participants in the later stages of dementia would not be able to communicate successfully, so informants were also interviewed, specifically family members or professional carers who knew the participants well. Their results demonstrated that some aspects of self continued to exist into the later stages of dementia, notably family roles.

2.5.4 Conclusions concerning stability and change in self

These studies provided evidence to support the assertion of Sabat and Harre (1992) that Self 1 is maintained in spite of dementia, and that Self 2 may change in some ways. There is also some evidence to suggest that despite others perceiving changes in Self 2, people with dementia still saw themselves

as the same, but through contact with others, they started to construct a new sense of self that accommodated their dementia. Furthermore, the studies suggested that if retained aspects of self are recognised by others Self 2 and Self 3 can be supported. There is, however, criticism that interview and observational methods based on individual case studies are context dependent, so may not be reliable or generalisable to a wider population. However, studies by Tappen et al (1999), Mayhew et al (2001), and Surr (2006) involved numbers of participants with dementia that were comparable to the experimental studies described in the early sections of the chapter, and studies by Cohen-Mansfield et al (2000,2010), involved considerably larger numbers of participants so could be regarded as robust and applicable to a wider population.

To summarise, the majority of the studies in this section based on social constructionism have demonstrated that various aspects of the self are affected by relationships and the social conditions in which a person with dementia is situated. Studies using social constructionist approaches have revealed that Sabat and Harre's models of self can provide useful ways to frame and inform investigations into self in dementia. These investigations have demonstrated that aspects of self can be retained, especially with the support of people with whom a person with dementia has a close relationship. The studies also provided evidence to show that even in the later stages of dementia, people can express meaningful aspects of themselves, actively continue to maintain previous identities, and may also be able to adapt to new ones.

The following section covers embodied selfhood which is especially relevant for people in the later stages of dementia who may have difficulty expressing themselves verbally.

2.6 Embodied Selfhood in people with dementia

Three studies were identified for inclusion in this section that investigated evidence for retained embodied self in people with dementia (summarised in Table 2.10). Firstly, Kontos (2004) echoed Merleau-Ponty and claimed that self persists in people with dementia because it is an embodied element of the human condition. Kontos proposed that it is characterised by observable understanding of a situation, the capacity to improvise according to abilities, and signs of 'being in the world' (Kontos, 2004, p.829). These capacities are sustained by the body's intrinsic abilities as well as by learning socio-cultural

Table 2.10 Studies Investigating Embodied Selfhood in People with Dementia

Study Authors	Study title	Participants	Component/s of self specified by authors	Main findings
Kontos (2004)	Ethnographic reflections on selfhood, embodiment and Alzheimer's disease.	13 adults with moderate to severe AD	Embodied selfhood	Participants demonstrated selfhood through bodily actions. They showed awareness of their surroundings and were able to engage with the world.
Ward & Campbell (2013)	Mixing methods to explore appearance in dementia care.	Adults with dementia in various sites including hospitals, day-centres, private and residential homes.	Communication and embodied selfhood	Authors reported need to understand embodied experiences of people with dementia to learn how people with dementia use their bodies and senses to create meaningful worlds.
Hubbard et al (2002)	Beyond words: Older people with dementia using and interpreting nonverbal behaviour.	10 adults with dementia attending a day centre 6 members of staff	Communication and embodied selfhood. Personal self Personality	Participants used and understood non-verbal behaviours, which helped them retain their sense of personal self. Were able to take on 'roles' of others in context of shared meanings and interpreting meanings of others' actions.

conventions. Kontos based this view on observations of 13 people living with moderate to severe cognitive impairments in residential homes. Her observations included evidence of embodied selfhood such as attention to physical appearance and social etiquette, gestural communication, and expressions of caring, personal preferences and individual style. These observations link with those made by researchers reported in section 2.5.2. Sabat (2002) emphasised the need for social engagement to enable the expression of Self 2 and Self 3, and Surr (2006) identified embodied aspects of self related to physical attractiveness, and suggested that theories of self should include embodiment in order to create a more holistic model of self. Similarly, by observing participants over multiple sites including hospitals, day-centres, private homes and residential homes, Ward and Campbell (2013) highlighted that engaging with the embodied experiences of people with dementia (such as hairdressing) can help in the understanding of how their bodies are used to make meaning in their worlds.

Furthermore, Kontos (2004) described expressions such as concern for appearance and social etiquette as being activated without a need for conscious thought; such actions represent aspects of our social and cultural selves (again echoing Sabat & Harre 1992) that are deeply embedded as habits that enable the activation of the body's natural expressive abilities which may not be affected by cognitive decline. This links with views of Burkitt (2002) who explored the notion of habit or "habitus". Echoing Merleau-Ponty, Burkitt described habits as dispositions that set in motion specific actions in specific contexts; an individual is aware of performing actions but will not necessarily know why. Burkitt claimed that humans will have been taught, or absorbed, habits and values from early childhood such as practical skills and moral virtues. For example, a person with dementia making humorous facial expressions (e.g. Hubbard et al, 2002, see below) may be demonstrating a habit that began in childhood which was an expression of his or her self at that time, suggesting that an aspect of him/herself is preserved.

Small et al (1998), followed a social constructionist approach (see also section 2.5.2), but also recognised the importance of non-verbal behaviours for demonstrating retained aspects of self. The researchers observed care home residents, who had been diagnosed with Alzheimer's disease and dementia-like

memory loss, during interactions between other residents and members of staff. Examples of non-verbal expressions of self included people defending their rights as individuals, such as wanting to sit in a particular chair, or to remain standing. However, echoing Sabat and Harre (1992), the authors reported that these actions were regarded as negative behavioural symptoms of dementia by care staff, rather than positive demonstrations of retained aspects of self.

Examples of meaningful non-verbal behaviours were also reported by Hubbard et al (2002), who investigated non-verbal communication in 10 people diagnosed with dementia whilst they were attending a day centre. The researchers identified many examples of meaningful behaviours such as physical contact and proximity to others in order to initiate conversation. These kinds of behaviours demonstrated retained aspects of self, that were related to social roles and the deeply embedded habits associated with those roles (Kontos, 2004).

To summarise this section, theories of embodied selfhood have provided evidence that people with dementia can continue to express themselves non-verbally through gestures and body movements that can be interpreted as meaningful expressions of self. Linking this with other disciplines, embodiment can be associated with social constructionism because some expressions may be learned implicitly through social interaction, and there may also be cognitive input in the form of implicit and procedural memories.

2.7 Discussion

The aim of this chapter was to investigate what is already known about self in dementia by drawing together the body of research across four broad theoretical approaches: cognitive, personality, social and embodied self. Both quantitative and qualitative methods have been used to study self in dementia, and within these paradigms, research designs have varied considerably, reflecting the varied models of self that underpinned the studies. These fundamental differences make it impossible to directly compare the results of these studies. However, the aim of the review is to provide a broad, in-depth account of how self is experienced and expressed by people living with dementia.

Studies that have not specified types of dementia should be interpreted with caution. For example, a person diagnosed with semantic dementia will have difficulty expressing him or herself verbally, and will have a reasonably intact memory, but if he or she cannot describe memories fluently, it may appear that the person's memory is also impaired. Conversely, a person with Alzheimer's disease may also have trouble describing memories, but in this case this would genuinely result from impaired memory function.

Also, as a person ages, they may experience sensory changes such as impaired hearing and eyesight that will affect their ability to perform tasks, so again results of cognitive tests should be interpreted with caution, as poor performance could be influenced by sensory and not only cognitive changes. Furthermore, it is necessary to consider the way evidence is interpreted by researchers because pre-existing beliefs will affect the way evidence is selected and reported. Thus, some studies only report evidence for or against persistence of self and do not consider contradictory evidence.

As mentioned in Chapter 1, measures used in quantitative studies, such as structured interviews and questionnaires, require intact comprehension and the ability to formulate answers quickly, which may be challenging for people even in the early stages of dementia. For this reason, methods used by qualitative researchers that are more sympathetic to a person's abilities have been highlighted, that may be preferable for gaining valid information. In view of this, these will be incorporated into the ways the new measure of self is administered; for example, carrying out tests in natural surroundings may reveal communication abilities that would not be observed in objective experimental settings.

An issue that occurs with some of the quantitative and qualitative studies presented in the review is small sample size, arising because of difficulties in obtaining large numbers of participants from clinical populations, and the ethical requirements that must be considered when wanting to involve people with impaired mental capacity. This means it is difficulty to claim generalizability of results, emphasising the need to repeat studies.

A final issue concerns the ways that different studies reflect the constructs of self that were defined in Chapter 1; some studies consider the self as multifactorial, whilst others focus on particular components of self. Traditionally

empiricist cognitive psychology and social constructionist approaches to self have remained distinct. However, this review has demonstrated that links can be made between disciplines and approaches, for example, to enhance understanding of embodied selfhood and autobiographical memory. This thesis will aim to develop knowledge concerning self in dementia by making these links explicit, basing the next research phase on the framework of self illustrated in Figure 2.7.

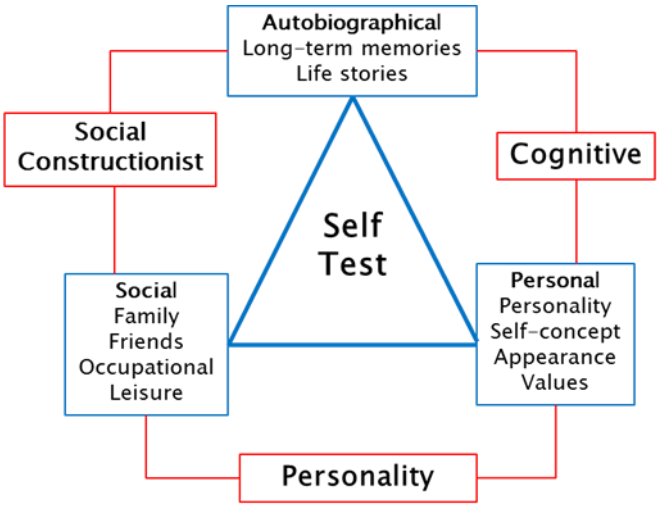


Figure 2.7: A Conceptual Framework of Self

This conceptual framework illustrates how the components of self are connected as revealed by investigating the different theoretical approaches. The blue framework represents the multiple components of self that were identified in the literature review as being relevant for people with dementia. The red framework demonstrates theoretical approaches that provide evidence to link the components of self. This framework will be used during the development to the new measure to ensure that all aspects of self are covered by it.

2.8 Summary: What has been learnt about self in dementia?

The literature review has demonstrated that it is possible to combine findings from studies associated with different disciplines, approaches and methodologies to provide a holistic view of self in dementia, specifically:

- Quantitative studies based on cognitive and personality theory have provided evidence to show that there is loss and change in sense of self

in people with dementia, specifically self-concept, identity, and some types of self-awareness.

- Studies focusing on autobiographical memory have demonstrated that not all types of memory are impaired in people with dementia; semantic memory has been shown to be relatively unimpaired in people with Alzheimer's disease, and these types of memory may continue to support a sense of self.
- Studies focusing on self-awareness have demonstrated multidimensional aspects of self, of which some aspects may be more impaired than others in people with dementia.
- Conversely, studies based on social constructionism and embodied selfhood have shown that aspects of self are retained, and that people with dementia can actively maintain their self and identity and learn to cope with their changing abilities and situations.
- Studies based on social constructionism and embodied selfhood provide a wealth of information that broadens the narrower understanding of cognitive studies. They have also demonstrated that links that have not previously been explored can be made between disciplines, for example social factors affect the ways memories are encoded and recalled.

Thus, integrating evidence from multiple disciplines has addressed a gap in the knowledge base concerning self in people living with dementia that can be used to develop a new, multifaceted framework of self that incorporates cognitive, personality, social and embodied aspects and expressions of selfhood into account.

Chapter 3 will present reasoned arguments for the methodology that was used for this research study, specifically aiming to combine experimental quantitative methods with investigative qualitative methods.

3. Methodology

"Psychical states, if they mean the varying conditions of my whole self, may at least in principle be compared and compared in amount"

(F.H. Bradley, 1895, p.3)

3.1 Introduction

The previous chapters have provided background to the research project and reviewed literature in relation to self in people with dementia. This chapter considers the ontological perspective of the PhD and the methodology.

3.2 Philosophical Paradigms

Paradigms are the belief systems or world views that guide investigators in their choice of methodology and methods (Guba & Lincoln, 1994). The dominant paradigm in the field of scientific research is positivism, which underlies experimental investigation and objective measurement in the natural sciences. Positivist approaches use scientific methods to discover accurate answers to research questions in order to reveal general truths or laws about the way the physical world works (Millar, 1999). This approach has been extended from the natural into physical and social sciences; it requires the collection of empirical data to allow measurement of variables and to minimise influences other than the core variable(s) of interest. Such data is usually analysed using statistical and mathematical models and therefore this approach is also typically 'quantitative' (Guba & Lincoln, 1994). To employ a positivist approach in psychological or social science implies a belief that human beings have real and measurable attributes and exist in a world of tangible, definable characteristics. Thus, the pursuit of knowledge is advanced in these areas using hypothetico-deductive methods. This means formulating theory-based hypotheses that can be tested experimentally in order to gain new knowledge, or support or question existing knowledge (Meheus,1999). Studies are usually undertaken in controlled settings, as this allows the influence of confounding or contextual variables to be isolated or minimised. This point leads to one of the criticisms of positivism which is that it is too reductionist. For example, critics question whether all natural processes can be reduced to chemical or physical happenings, and

likewise social processes reduced to relationships between the actions of individuals.

An alternative paradigm is interpretivism (which can also be called constructivism), which was developed to address limitations of using a positivistic approach to the understanding of human beings and their experience. The interpretivist view is based on the belief that human knowledge is constructed through our experience of the world and social relationships. From this perspective an independent, objective reality does not exist; there can be any number of worlds, shaped by human minds (Praetorius, 2003), so knowledge of the world cannot be gained via a single scientific method but needs to take individual meaning and interpretations into account. Associated research methods involve in-depth interpretation of verbal accounts given by individuals, of their experiences, beliefs and values, aiming to explain how people make sense of the external world in which they live.

These two paradigms represent widely held complementary philosophies. In terms of sense of self, the literature review demonstrated that both paradigms can provide information about how self is manifested in human beings, and how individuals with dementia perceive and describe their own sense of self. However, the purpose of this study is to develop a *measure* of self which is in itself suggestive of a positivist approach. Theories grounded in cognitive psychology have been used for measuring self in people with dementia, however, studies using interpretivist approaches have identified that such methods are inappropriate for administering to people with dementia, because they do not focus on the socially constructed nature of self.

A related question is whether self is objectively lost for people with dementia, or whether it is theirs' or others' perceptions that self is lost. A loss of self could be explained in different ways:

- *Neurodegeneration of the brain.* For example, cognitive psychologists might suggest that self is lost because people are unable to lay down new memories, but other evidence from cognitive approaches suggests that self per se is not lost, but limited access to, and retrieval of, memories create the impression that self is lost.

- *A person's ability to communicate aspects of the self is affected by the disease process.* For example, Davis (2004) suggests that a person's lived experiences create knowledge of their self 'being-in-the-world, and that dementia 'derails' this process, leading to impoverished feelings of 'being', that affect a person's sense of self and their ability to communicate with others.
- *The social situation and wider attitudes of society obstruct a person's ability to express their self.* For example, Sabat (2005) argues that people living with dementia continue to be 'semiotic' people which means that their behaviour continues to be motivated and driven by an understanding of the world around them. Thus people with dementia can understand and evaluate how they are treated by others, and an inability to express themselves may be brought about by disabling social situations, not solely neuropathology. Furthermore, frustrations and anger caused by such situations may exacerbate the neuropathological effects making a person even more incapacitated.

This research project will not be able to answer the fundamental questions concerning deterioration of self itself, or the impaired ability to communicate a sense of self, but it will be firmly grounded in the belief that the external situation can affect the way a person responds to questions and thus the ease or difficulty they may have in expressing themselves.

In conclusion, the goal of developing an objective measure of self means that this project's methodology will be predominantly positivist, shaped by interpretivist findings. This corresponds with the view of Michell (2009) that positivism should not be identified solely with the isolation and measurement of discrete variables because psychological attributes such as self-concept are constituted within sociocultural and historical aspects of human life (Martin,2003), thus incorporating qualitative interpretivist approaches.

The following sections will address ontological and epistemological issues relevant to the project's aim of developing an objective measure of self in people with dementia.

3.3 Ontology

Ontology concerns the form and nature of reality, what is known, and what can be known about reality. Thus ontological enquiry must relate to real phenomena (Guba & Lincoln, 1994). The phenomenon under investigation in this study is sense of self, which is a psychological 'attribute'; whether a psychological attribute can be considered a 'real' phenomenon requires consideration (Martin, 2013; Maul, 2013). An ontological position allied with positivism is realism (Guba & Lincoln, 1994; Maul, 2013) which states that some phenomena exist independently from the mind and therefore can be measured scientifically (Maul, 1994). This poses the question of whether the subjective sense of self can be considered as being independent of the mind. These questions can be investigated with relation to the ontological position of 'Scientific Realism' (Maul, 2013). This position combines the traditional realist view with the belief that by building robust scientific theories helpful explanations can be provided of both observable and non-observable aspects of the world, including psychological attributes (Maul, 2013). Therefore, scientific realism is an appropriate stance to adopt in order to obtain a useful account of the sense of self of people living with dementia.

Conversely, an ontology allied to interpretivism is relativism which asserts that realities exist as multiple, subjective mental constructions that depend on the cultural and social situations, experiences and interactions of individuals or groups. Exploring these subjective perceptions and 'lived experiences' has value when researchers aim to explain how and why people with dementia experience loss or change of self, but is not as helpful for determining objectively how sense of self can be measured. Many of the studies reviewed in Chapter 2 took an interpretivist approach and the design of the measure has drawn upon interpretivist studies whilst still taking a realist stance.

3.4 Epistemology

Epistemology concerns the methodological relationship between the knowledge to be discovered and the "would-be knower" (Guba & Lincoln, 1994, p.108), and the type of knowledge that the methodology aims to produce (Willig, 2001). This project aims to develop an objective measure of self that can be used by anyone (would-be knowers) with minimal training, in order to provide knowledge

concerning sense of self in people with dementia in the form of reliable and valid outcome measures.

Sense of self is a psychological attribute and as stated in Section 3.2 psychological attributes are best considered as being situated within social and historical contexts, including the context of living with dementia. This echoes the view of Goldman (1986a) who proposed that human knowledge should be viewed as being shaped by psychological and social factors. He developed a conceptual epistemology that combines cognitive and social knowledge, proposing that primary (cognitive) epistemology is concerned with cognitive processes, structures and mechanisms, and secondary (social) epistemology requires the investigation of how different patterns and arrangements of social intercourse affect the way truth is acquired. Praetorious (2000) similarly claims that human cognition is constructed through interaction between individuals and the world and that in order to understand human psychology, other factors should be taken into account, such as context, physical environment and social relationships.

An opposing epistemological approach associated with interpretivism is social constructionism. Advocates of this approach claim that knowledge is socially constructed (Willig, 2001), and knowledge is formed in the context of socially agreed customs and practices (Praetorious, 2003). During the research process there is a reciprocal relationship between the researcher and person being studied such that participants' and researchers' interpretation of events contribute to the research findings. Therefore, from a positivist perspective, the requirement of researcher objectivity is compromised, and for this reason, a purely social constructionist approach to this study is not appropriate.

However, in this project these approaches will be combined. Toomela (2008), a cognitive psychologist, argues for interpretivist input into positivist studies, so that psychologists can consider the meaning of facts as well as analysing facts statistically. Sabat (2014), who promotes social constructivism, asserted that intact psychological, cognitive and emotional abilities of people with dementia cannot be identified by their performances on standard neuropsychological tests. In other words, quantitative analysis alone could not provide a complete understanding of what a person with dementia experiences. A fuller understanding could be achieved by combining qualitative analyses with the

examination of quantitative data. To date there have been few published studies taking this type of combined approach to researching self in dementia; therefore, this study will be novel by being driven by a cognitive approach whilst incorporating methodologies associated with qualitative disciplines.

Chapter 4 will report the preliminary stages of development of the new Measure of Self, including planning and collecting together the contents of the measure, devising methods of administration, and piloting the first version whilst considering the requirements of people living with dementia at all stages.

4. Methods: Measure Development and Pilot Study

"Morris and I are far more than diseased brains. We each have a unique personality with emotions, experiences and a place in a social world."
(Bryden, 2015, p.17)

4.1 Introduction

The previous chapters introduced the research topic of self in dementia, reviewed the literature concerning methods of investigating self in people with and without dementia, and outlined the methodological approach to developing a new objective measure of self. The remaining chapters of this project concern the development (i.e. content and administration) and validation of the Measure of Self following a seven-stage measurement development process, advocated by Smith et al (2005), illustrated in Figure 4.1. This process ensured that the development of the Measure of Self followed a rigorous and established approach to measure development and validation (Rattray & Jones, 2007).

There are already a wide range of existing validated measures of self, reviewed in more detail in the first stage of the development process. In developing a measure of self appropriate for people with dementia, the first stage in the process was to select a pool of measures designed to measure cognitive, social and embodied aspects of self. The new measure was constructed by adapting and combining elements of existing measures of self to ensure that it was suitable and valid for use with people with differing levels of communication abilities, and could be used to gain a rounded, holistic measure of self. This chapter describes the development and piloting of the Measure of Self by reporting Stages 1 to 3 of Figure 4.1, including justification for the methods used. Following this, Chapter 5 reports Stages 4 to 7 of Figure 1, presenting Study 2 which investigated the psychometric properties of the Measure of Self in terms of test-retest reliability and convergent validity.

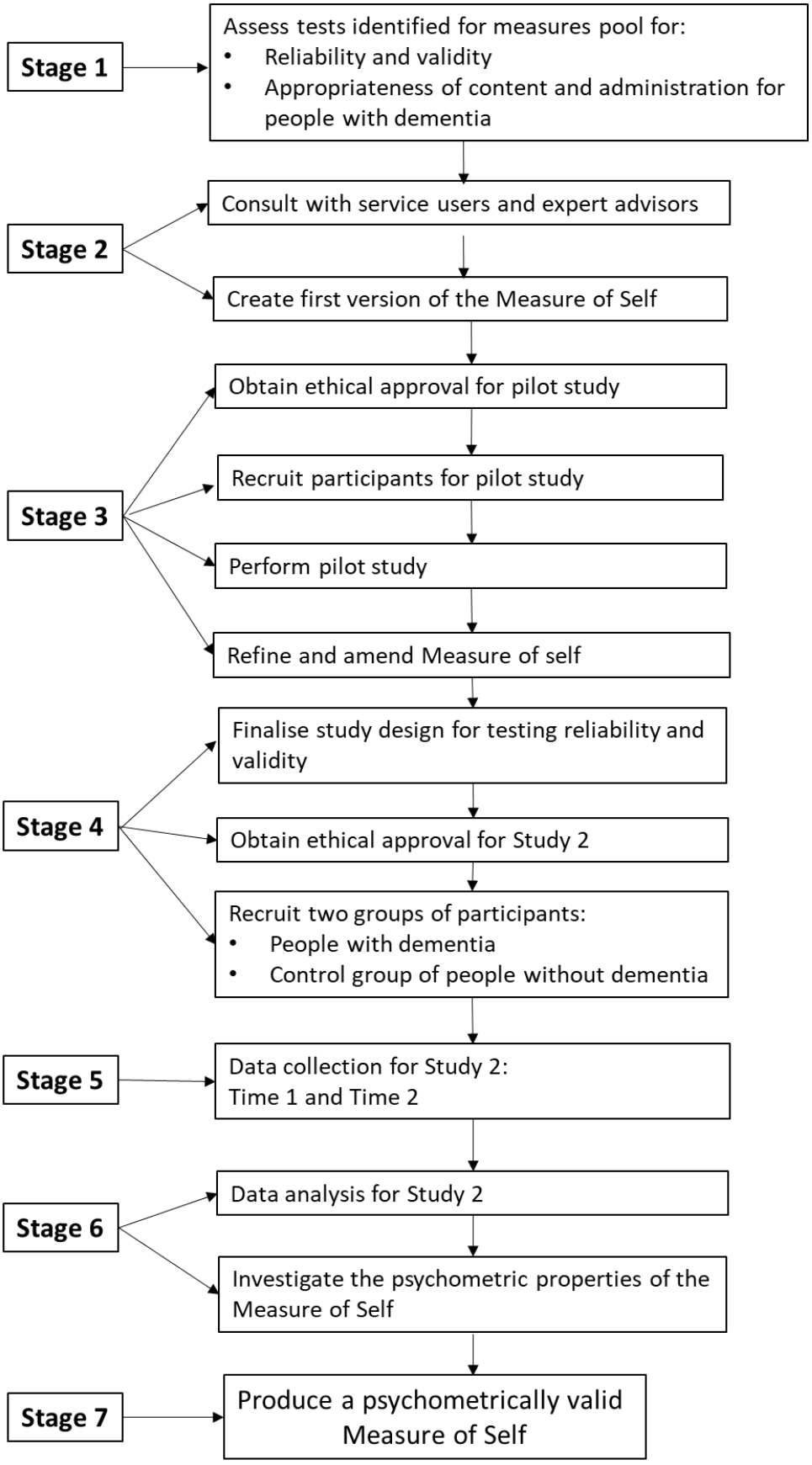


Figure 4.1 Seven-stage Measure Development Process

4.2. Stage 1: Creating a pool of measurement tools related to self and identity

The literature review described in Chapter 2 identified 23 studies that used measures focusing on self, identity, autobiographical memory and personality, some of which have been used with people with dementia. Stage 1 of the development process was addressed by assessing which of the 23 measures were suitable to be further assessed by expert advisors for using as a basis for the new Measure of Self. The 23 measures were chosen because they covered multiple aspects of self based on cognitive, social or embodied approaches. They are summarised in Table 4.1.

Table 4.1: Measures of Self, Identity, Memory and Personality

Name of Measure	Aspects of Self Covered
Adjective Checklist/Creative Personality Scale (Gough, 1979)	Identifying creative talent within an individual.
Autobiographical Interview (Levine et al, 2002)	Focus on episodic and semantic features of autobiographical memories over different lifetime periods. Used to identify age-related changes in autobiographical recall.
Autobiographical Memory Interview (AMI, Kopelman et al, 1990)	Recall of semantic facts and specific episodic memories from three time periods: childhood, early adulthood, recent times. For use with amnesic patients and healthy controls.
AMI-Extended (Naylor & Clare, 2008)	As AMI with additional middle-age time period.
Brooks and McKinlay Personality Inventory (Brooks & McKinlay, 1983)	Assessment of personality change over time.
IMAGE Test (Eustache et al, 2013)	Measures three components of self-concept: identity, behaviour and self-satisfaction.
Life Orientation Test (LOT, Scheier & Carver, 1985)	Measures tendency to be optimistic, i.e. a person's expectations of good or bad outcomes.
Personal Self-concept Questionnaire (PSCQ, Goni et al, 2011)	Four scales measuring personal, as opposed to social, self-concept: i) self-fulfilment, ii) autonomy, iii) honesty, iv) emotional self-concept.
Physical Self-concept Scale for Older Adults (PSCS-OA, Hsu & Lu, 2013)	Examines physical characteristics and abilities of older adults.

Name of Measure	Aspect/s of Self Covered
Questionnaire of Self-representation (QSR, Duval et al, 2012)	Examines self-concept: physical, moral, personal, family, cognitive, social, emotional.
Rosenberg Self-Esteem Scale (Rosenberg, 1965)	Examines thoughts and feelings about one's worth and importance.
Self and Identity in Dementia Questionnaire (SIDQ, Cohen-Mansfield et al, 2000)	Examines four kinds of role identities: i) professional, ii) family-role, iii) leisure activities, iv) personal attributes.
Self-concept and Identity Measure (SCIM, Kaufman et al, 2015)	Self-report questionnaire to identify healthy and problem identity functioning and personality disturbance.
Self-consciousness Questionnaire (S-CQ, Gil et al, 2001)	Examines aspects of self-consciousness: identity, knowledge of cognitive impairment, affective state, physical state, prospective memory, capacity for introspection, moral judgement.
Self-consciousness Scale (SCS, Fenigstein et al, 1975)	Examines private self-consciousness: beliefs, aspirations, values and feelings, and public self-consciousness: overt behaviour, mannerisms, and expressive qualities.
Sense of Belonging Scale (Hoffman et al, 2002-3)	Measures experience of feeling part of a group or environment.
Social and Personal Identities Scale (Nario-Redmond et al, 2004)	Examines social identity: categorising oneself in terms of group identities, and personal identity: self distinct from in-group relationships.
Tennessee Self Concept Scale II (TSCS-II, Fitts, 1965)	Measures multi-dimensional self-concept: physical, moral, personal, family, social, academic/work.
The 3-I Test (Duval et al, 2012)	Assesses structural identity: trait self-knowledge, autobiographical memory, and functional identity: self-consciousness, self-projection, related to past, present and future
The Oral I-AM Test (Eustache et al, 2013)	Asks for 10 'I am' statements classified as: 'Idiocentric' = personal qualities, attitudes, states, physical features, preferences. 'Small-group and large group'= interdependent self. 'Allocentric' = traits and preferences dependent on other people's viewpoints.

Name of Measure	Aspect/s of Self Covered
The Relational, Individual and Collective Self-aspects Scale (RIC, Kashima & Hardie, 2000)	Measures self-aspects: i) 'Relational': relationships, interpersonal roles, characteristics shared with others. ii) 'Individual': personal, private, idiocentric, autonomous. iii) 'Collective': derived from membership of groups and social categories.
Thinking About Life Experiences Scale (TALE, Bluck & Alea, 2011)	Measures 3 functions of autobiographical memory: i) Self function: to maintain sense of being the same person over time. ii) Social function: to develop, maintain and enhance social bonds. iii) Directive function: to guide present problem solving and direct future behaviours and thoughts.
Twenty Statements Test (TST, Kuhn & McPartland, 1954)	Asks for 20 answers to the question 'Who am I?' to identify and measure attitudes about oneself.

Assessing the pool of measures for reliability and validity and use with people with dementia

The next stage of assessing the quality of the 23 measures entailed consideration of whether the measures had been tested for reliability and validity. There are a variety of ways of testing measurement tools for reliability and validity; the following methods were identified as having been used to assess the quality of the 23 measures. See Appendix I for a table summarising reliability and validity as reported for each measure.

Reliability refers to the internal consistency, stability, and ability to be applied to a wider population. This means the extent to which the tool produces the same results each time it is used (known as test-retest reliability), that all components of the tool measure the same phenomena, in this case, aspects of self (tested by split-half reliability) and the extent to which different investigators using the measure produce the same scores (inter-rater reliability). Each type of reliability is explained more fully below:

Test-Retest Reliability assesses the consistency of a test across time. It requires that the same test is used with the same group of participants on two separate occasions. The two sets of data are correlated with each other to

determine whether or not the participants produce the same score on each occasion. High reliability is demonstrated by a value of 0.75 to 0.8 (Coolican, 2004). The length of time between presentations should minimise the risk of participants remembering their previous responses, but not be so long that the phenomenon being measured would have fundamentally changed. A suggested time scale in clinical settings is more than one day and less than one month (Watson, 2013).

Inter-rater or Inter-observer Reliability assesses the level of agreement between raters or observers. The aim is to ensure that a measurement tool will produce the comparable results regardless of who administers the test. One method is for two investigators to administer the same test to the same participants, and the results are compared by correlation (Watson, 2013).

Validity demonstrates that a measurement tool measures what it is intended to measure. There are several types of validity that are relevant to the measures of self and identity (adapted from Rattray & Jones, 2007):

Construct Validity relates to how well the content of the measure represents the underlying concept; it is usually assessed by factor analysis which looks for correlations between sub-scales or sub-classes of a measure.

Convergent Validity is a sub-type of construct validity that is demonstrated by comparing the measurement tool that is being assessed with a related measure in order to demonstrate a correlation between the two measures.

Discriminant Validity is also a sub-type of construct validity and is demonstrated by correlating the tool with an unrelated measure with the expectation that the two measures will not show a strong relationship with each other.

Content and Face Validity require the opinions of experts who should agree on the soundness of the content of the measurement tool and therefore should be experts in the phenomenon being tested. Face validity can also be assessed by the general public.

Criterion or Concrete Validity relates to how data from the new measure relates to other known data in ways that can be predicted. It is often divided into concurrent and predictive validity.

Concurrent Validity is demonstrated by comparing the measurement tool with a similar test or older version of the new test.

Predictive validity is the extent to which scores on a new test predict scores on a test that is measuring the same phenomenon.

External Validity assesses whether the findings of a particular measure can be extended to a population

The third stage of assessment involved consideration of whether reliability had been assessed in studies involving people with dementia; each of the 23 measures was scored according to the following criteria:

1. Evidence of assessment of reliability and validity, based on the above types and definitions, with people with dementia.
2. Whether or not the scoring and administration of the measure were adapted for, or specifically designed for, people with dementia.
3. Use with people with different types of dementia and at different stages of the conditions.
4. Numbers of participants with dementia who completed the measure.
5. Components of the framework of self that were covered by the measure.

Each study was graded by:

- Being allocated scores of 0 or 1 according to whether points 1, 2, and 3 had been reported, i.e. 0 indicated that none of the points were addressed, 1 indicated one of the points, 2 two points, and 3 that all the points were addressed
- For point 4, up to 20 participants with dementia scored 1, up to 40 scored 2, and more than 40 scored 3.
- For point 5 the score was simply the number of components of self shown in Figure 2.6 that were covered, the maximum score would be 6.

Total scores (maximum 12) were calculated and details of 16 measures with the highest scores were sent to the expert advisors (see Appendix I for a table showing the scores for each measure). It should be noted that none of the measures scored more than 5, this demonstrates that no existing measure covers the multiple aspects of self, and methods suitable for people with dementia, that are the aims of the proposed Measure of Self.

Seven of the measures were discarded, based on the criteria listed above. Six were discarded because they had not been used with people with dementia; one measure (the Self-Consciousness Questionnaire) involved people with dementia, but the number of participants was small (n=18). Furthermore, the questionnaire consisted of a small number of questions (n=14) aiming to cover seven aspects of self-consciousness so none of the aspects were covered in depth. Table 4.2 gives more details of the reasons for the seven measures being discarded.

Table 4.2: Measures Considered Unsuitable for Further Consideration

Measure	Reasons for discarding
Brooks and McKinlay Personality Inventory	• Validity only reported for participants with head injury • Test-retest reliability for personality ratings given by care givers only • All participants were care givers of people with dementia, no participants had diagnosis of dementia • Only personality traits covered
Personal Self-concept Scale	• No reliability assessment • No participants with dementia, none over 65, majority adolescents and university students. • Only personality aspects of self covered
The Relational, Individual and Collective Self-Aspects Scale	• No participants with dementia, undergraduate students only. • Only social aspects of self covered.
Self-Concept and Identity Measure	• No participants with dementia, undergraduate students only. • Used to identify individuals with identity confusion or disturbance in clinical settings.
Self-Consciousness Questionnaire	• No validity assessment • Looking for deficits and impairment of private and public self-consciousness related to AD
Self-Consciousness Scale	• No validity assessment • Developed for student population only
Thinking About Life Experiences Scale	• No participants with dementia. • Emphasis on functions of autobiographical memory rather than content of memories.

The 16 remaining measurement tools were selected to be sent for review by expert advisors (section 4.2.3.). Written details of each measure were sent along with copies of Table 4.3, which summarised indicators of the criteria listed above and, if specified, the stages and types of dementia of the participants. The table also includes a column in which a diagram of the Model of Self highlights the relevance of each measure to the model by indicating which aspect/aspects of self are covered by the measure.

4.2.2 Stage 2: Consult with service users and expert advisors

A key component of this research study was to take advice from representatives of the population who would ultimately benefit from the research (people living with dementia or 'service users'), and from experts who have conducted research into self, and specifically self in people with dementia ('expert advisors'). The intention of these consultations was that they would contribute to the face and content validity of the Measure of Self, meaning that it would be representative of the concept it was intended to cover, for the population who would be asked to complete it.

Service users

This stage in the development of the Measure of Self aimed to determine, by consulting people living with dementia, what 'self' meant to them, and if people with dementia were willing and happy to talk about themselves. Three residents of a dementia care home, who were members of the University of Bradford Experts by Experience panel, were consulted. Experts by Experience are people who have specialist knowledge, through their experience as service users (McLaughlin, 2009). Care home residents, with moderate to severe dementia were consulted as this is the group that the Measure of Self is aimed at helping the most, because risk of loss of self is more likely as the condition progresses. The three residents were 'Eric', 'Sandra' and 'Geoff' (pseudonyms). The researcher talked to them informally, asking questions such as what having a sense of self meant to them, and how they described themselves. Notes of the questions and replies are presented in Appendix II. The conversations demonstrated that these three people with dementia could talk about their current and past selves, and that different aspects of self (associated with the Model of Self in Chapter 2), such as personality, family and social roles and activities were still important to them. For example, Sandra thought that having

a sense of self meant that someone was taking notice of her (i.e. social aspect of self), whereas Eric talked about his past life and personality traits (i.e. individual aspects of self). Thus, the aspects of self that were identified from the literature review as being important for providing a holistic view of self were also identified by experts by experience as being important to them, and therefore appropriate for including in the Measure of Self.

Expert Advisors

Professor Steven Sabat, Professor Pia Kontos and Dr Clare Rathbone consented to act as expert advisors for the project. They were invited because of their expertise and knowledge of social constructionism, embodied selfhood, and experimental research into self and autobiographical memory in people with and without dementia, consequently their studies featured in the literature review. The purpose of consulting expert advisors was to gather a range of expert opinions to inform decisions made about the content and methods of administration of the new measure, such that these elements would be appropriate for people at different stages of dementia.

With the aim of "getting the most from a panel of experts" (Davis, 1992, p. 194), each panel member was sent details of the objectives of the instrument and its purpose, with details of the questions to be considered. To this end, interviews were arranged with each of the experts in person or via Skype. Given the differing theoretical and methodological backgrounds of the three experts they were asked to only comment on measures that were representative of their area of expertise.

Questions for the expert advisors

A set of questions was sent to the experts before their interviews to allow the gathering of their opinions. Details of the administration of all 16 measures (see Appendix III) and Table 4.3 were sent with the questions, which were as follows:

General overview of a new measure of self:

1. What do you think are the most important points to consider when developing an interview-based measure of self for people with dementia?
2. What are the main challenges?
3. Is it feasible for [the researcher] to devise one measure that will cover differing levels of ability, or should there be two versions of the measure?

***With reference to the conceptual model of self on which the measure will be built*:**

4. Is the model self-explanatory or do you have any queries about it? Are there any aspects of self that you think should be included in the diagram?

With reference to the 16 measures summarised in the table:

5. What are your first thoughts about the measure and how applicable is it for people with dementia?

6. Does the measure relate to a 'holistic' view of self or specific aspects of self, with reference to the model?

7. Could the test be adapted so that it does not have to rely as heavily on verbal communications, e.g. by use of pictorial or object cues when asking the questions, and pointing at words or images, or observation of gestures for responses?

8. Do you have any comments about the instructions for participants and/or methods of analysis of their responses?

Responses from the expert advisors and actions taken

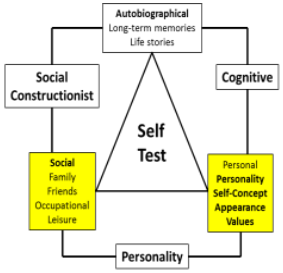
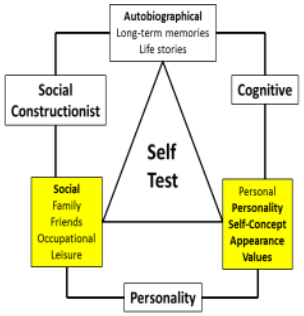
A summary of the responses given by the expert advisors is presented in Appendix IV, and sample transcripts of their interviews can be found in Appendix V. The key points gathered from the advisors were:

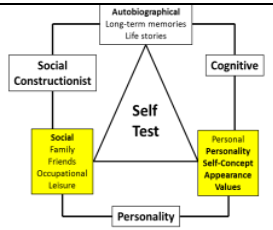
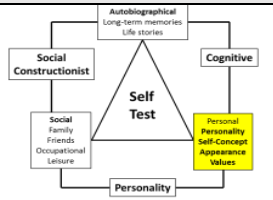
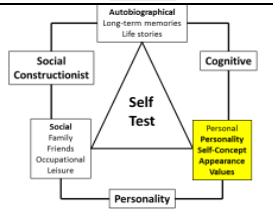
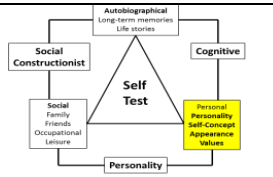
1. The most important points to consider when developing an interview-based measure of self for people with dementia.

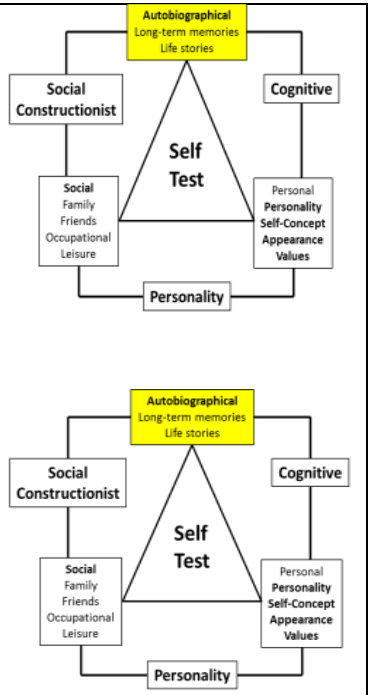
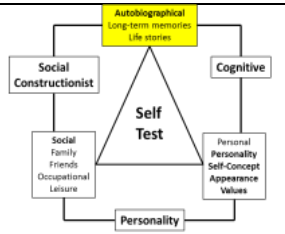
i) CR: Self is multifaceted so a tool needs to cover all aspects, but one tool that covers all aspects may be too complex for non-experts to deliver. One option is to produce a tool that covers one aspect of self in depth, that also enables people with advanced dementia to describe their identity.

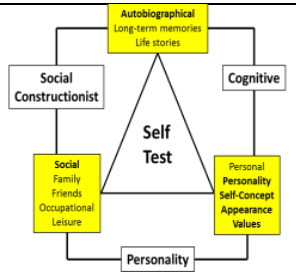
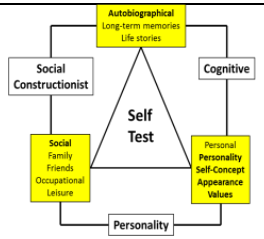
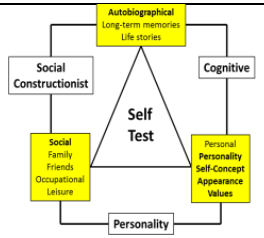
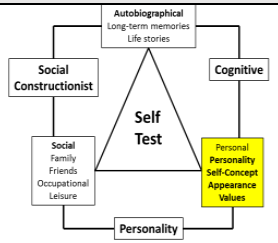
ii) SS: The researcher needs to establish trust and rapport with the participant. This may take more than one visit in order for the participant to trust the researcher. They may not remember the researcher's name, but they will remember a feeling that they have with the researcher as it builds up over time.

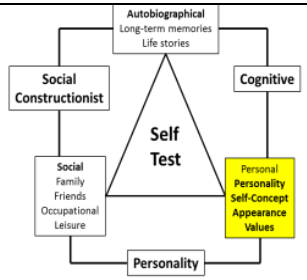
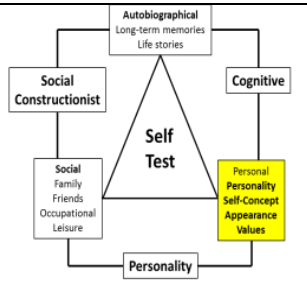
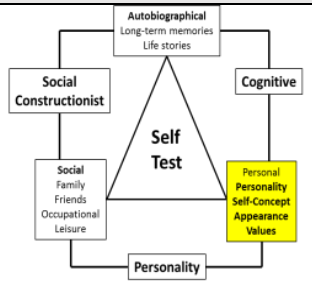
Table 4.3 Measures Sent to Expert Advisors

Name of measure + relevant Studies	Reliability General	Validity General	Reliability/ Validity pwd	Used with pwd	Type of dementia	Severity of dementia	No. of ppts	Relevance to model of self – aspects highlighted
Measures focusing on personal and social aspects of self								
1. Self and Identity in Dementia Questionnaire Cohen-Mansfield et al, 2000, 2006, 2010	Internal consistency = 0.83 Test-retest reliability = 0.86			Yes (3 studies)	Dementia	Mean MMSE = 8.7 Mean MMSE = 10.58 Mean MMSE = 7.2	38 93 193	
2. Social & Personal Identities Scale Nario Redmond et al, 2004	Internal consistency = 0.8 for personal scale; 0.79 for social scale. Test-retest reliability= 0.77 for personal scale; 0.82 for social scale.	6 studies demonstrated criterion and construct validity c.f. similar measures of identity		No (6 studies)			>1000	

3. Sense of Belonging Scale Hoffman et al, 2002-3 Tovar & Simon, 2010	Internal consistency = 0.9	Convergent validity established c.f. one measure of goodness of fit (CFI)		No			463	
Measures focusing on personality scales								
4. Adjective Check List/Creative Personality Scale Gough, 1979	'Interjudge' reliabilities ranging from 0.73 to 0.98	Criterion validity = 'moderate'		No			>1600	
5. Life orientation Test (LOT) Scheier & Carver, 1985	Internal consistency = 0.76 Test-retest reliability = 0.79	Convergent and discriminant validity demonstrated		No			150	
6. Rosenberg Self-Esteem Scale Rosenberg 1965 Martin-Albo et al, 2007	'Good' internal consistency and test-retest reliability	'High' construct validity c.f. other measures of self-concept		No			420	
Measures focusing on autobiographical memory								
7. Autobiographical Memory Interview (AMI) Kopelman et al, 1989	Reliability = 0.83 to 0.86	'Positive' concurrent validity c.f. 'Famous Personalities' test and 'Crovitz Test'. Differential validity: 'discriminated		Yes	Vascular dementia	'Moderate'	3	

Addis & Tippet, 2004 **8.AMI-Extended** Naylor & Clare, 2008 (additional 'middle age' time period) Subramaniam et al. 2014		significantly' between 'amnesic' participants and controls.		Yes Yes Yes	Alzheimer's disease Mixed dementias Dementia	Mild to mod. MMSE = 13 to 24 Mild to mod. MMSE = 16 to 29 Mild to mod re. CDR	20 30 24	
9. Autobiographical Interview Levine et al, 2002	Inter-rater reliability = 0.79 to 0.96	Construct validity = 0.68 c.f. AMI		No			30	
Measures based on "I am…" methods								
10. Twenty Statements Test (TST) Kuhn & McPartland,	Test-retest reliability = 0.85	Coefficient of reproducibility = 0.9						

1954 Addis & Tippet, 2004 Rathbone et al, 2008 (Ten Statements)				No Yes No	Alzheimer's disease	Mild to mod. MMSE = 13 to 24	20	
11. The Oral I-AM Test (10 statement version of TST) Eustache et al, 2013			Test-retest reliability demonstrated	Yes	Alzheimer's disease	Mean MMSE = 14	16	
12. The 3-I Test Duval et al, 2012 (adapted from TST)				Yes	Semantic dementia	Early to mod. MDRS mean = 117	8	
Measures based on self-concept scales								
13. Tennessee Self-Concept Scale II (TSCS-II) Fitts, 1965 Addis & Tippet, 2004	Series of exploratory and confirmatory factor analysis	Convergent and discriminant validity determined c.f. 'Self-description Questionnaire III		No Yes	Alzheimer's disease	Mild to mod. MMSE=13 to 24	343 20	

14. The IMAGE Test Eustache et al, 2013 (Adapted from TSCS-II for people with Alzheimer's disease)			Test-retest reliability demonstrated	Yes	Alzheimer's disease	Mean MMSE = 14	16	
15. Questionnaire of Self-Representation (QSR) Duval et al, 2013 Eustache et al, 2013				Yes Yes	Semantic dementia Alzheimer's disease	Early to mod. Mean MDRS = 117 Mean MMSE = 14	8 16	
Measure of physical self-concept								
16. Physical Self-Concept Scale for Older Adults Hsu & Lu, 2013	'Preliminary' reliability and confirmatory factor analysis established.	Content validity determined by pilot study. Construct validity = 0.65 +0.75 c.f. measures of subjective wellbeing		No (2 studies)			10 (pilot) 233	

Key: pwd = people with dementia; MMSE = Mini Mental State Examination; CDR = Clinical Dementia Rating Scale; MDRS = Mattis Dementia Rating Scale

iii) PK: There is tension between the different discourses on selfhood; measuring self is associated with a particular discipline (cognitive psychology) so incorporating work associated with embodied self may be problematic. Theoretical backgrounds of the perspectives that are incorporated must be explained. Can one measure capture self that is complex, multidimensional and multifaceted?

Actions taken:

i) It was decided to develop a measure that covered multiple aspects of self because findings from the literature review (Chapter 2) emphasised the importance of taking a holistic view, and that people with dementia find some aspects of self easier to describe than others. This could be due to their cognitive problems but could also be because people with and without dementia place different levels of importance on different aspects of self. The measure was developed so that it is simple to present and to record data, so that non-experts would not require extensive training in order to administer it.

ii) Where possible, the researcher made herself known to participants before they agreed to take part in the study and arranged to visit them in their homes or somewhere familiar to them. Some participants lived with a partner or carer who was able to remind them that the researcher was visiting and prepare them for the interview. The researcher phoned the participant, partner or carer before the visit to ensure that they were still happy to be interviewed.

iii) The theoretical approaches for all aspects of the Model of Self and ways of investigating and measuring sense of self and identity were covered in the literature review, and a reasoned proposal for combining embodied selfhood with social and cognitive approaches was given at the end of the review.

2. The main challenges to producing an interview based measure

i) CR: There is a tension between producing a measure that taps into all aspects of self in a sophisticated way but that can be delivered briefly to people with cognitive impairment, especially in care homes. It should not need a large number of props which will be unwieldy. Therefore, as a starting point, take a simple option which could be developed later. It is not useful to develop a very complicated tool that is never used.

ii) SS: The researcher needs to know not what a person feels but why they feel as they do, which takes time for the participant to establish trust with the researcher.

ii) PK: How can expressions of self be observed and their meanings understood? For example, behaviours regarded as symptomatic of dementia may have specific meanings in specific contexts. Previous occupations may be relevant so how can the researcher learn about these without lengthy investigation?

Actions taken:

i) The new Measure of Self was based on existing measures that have been widely used to measure aspects of self covered by the Model of Self. Their methods of administration were considered and only those that could be performed verbally, or with simple 'pencil and paper' materials were added to the pool of measures. These materials were adapted by combining them with visual cues (stimuli) to act as prompts for memory recall.

ii) A person-centred approach was taken by the researcher. For example, if a spouse or carer was present, the researcher kept her focus of attention on the participant, often repeated that there were no right or wrong answers, and that whatever the participant said was noted.

iii) The pilot study for the Measure of Self incorporated observational methods by using video recordings of the interviews to observe gestures and facial expressions that enhanced or emphasised what the participants said. These were used to create an observational checklist (section 4.5.5) that was used to interpret the responses of participants who were unable to express themselves verbally. Previous occupations formed part of one set of stimuli (section 4.2.3) so it was possible to take note of these.

3. The feasibility of devising one measure covering differing levels of ability

i) CR: One measure is preferable so that results can be compared over time and between different groups; it is not reliable to use different levels of questions for different stages of a condition. Similarly, if participants stop at different stages during a measure it is difficult to compare results.

ii) SS: Converting words into numbers is difficult, it must be clear what the numbers signify. The researcher may have to adjust their way of talking to a participant to meet their level of understanding, e.g. using different words, repeating things, providing an example, which are not usually possible with strict measurement tools.

iii) PK: Regarding cueing memories to help people of differing abilities, the way the cue works may affect how the person completes the measure so it will be difficult to standardise the results. If the cue does not work, there is a need to consider why the cue did not work.

Actions taken:

i) Having a single measure was the most practical option in terms of putting together materials for the Measure of Self that were generic and recognisable for all participants. The 'questions' (i.e. stimuli) were based on the answer to two simple questions "Who am I?" or "Who was I?" therefore there was no grading of questions as the interview progressed. The pilot study investigated the suitability of the materials and demonstrated that participants were able to remain engaged over the timespan of the interview, and that their results could be compared effectively.

ii) The methods of administration and numerical outcome measures for the first phase of the Measure of Self were based on the format of the Twenty Statements Test (Kuhn & McPartland, 1954) which has short and simple instructions, that can be repeated if necessary without affecting the response of the participant. The second phase of the Measure of Self was also based on questions and scoring used in the Autobiographical Memory Interview (Kopelman et al, 1990) which have been standardised and shown to be valid if prompts are given for memory recall. Thus the administration of the Measure of Self is based on well-used outcome measures and standardised questions that allow for prompting without negating the results.

iii) The pilot study investigated the effectiveness of generic images as cues, rather than images tailored for individuals; see also section 4.2.3 for details of how the type of stimuli used was determined.

4. With reference to the conceptual Model of Self, is it comprehensible and are there aspects of self that could be added to it?

i) CR: The diagram covers much of what can be described as ‘self-knowledge’ described by James (1890), i.e. ‘me’ (how people describe me), but omits ‘I’, which is self-consciousness and more difficult to observe and quantify. ‘Thinking about the future’ could be added; current research into this is in the early stages.

ii) SS: Some aspects (e.g. personality, self-concept) vary according to the situation and some are interconnected (e.g. personality with family, friends and occupation) so the interconnectedness of the diagram is appropriate.

iii) PK: There are other kinds of self-expression that can be included such as religious practices, creativity (singing, dancing, painting), behaviours that express previous occupations, etiquette, relationships.

Actions taken:

i) The Model of Self can be traced back to James (1890) because it was influenced by his quotation cited in Chapter 1. Aspects of self-consciousness were considered in the literature review (Chapter 2) which demonstrated that self-consciousness is multifaceted, for example, life history, moral stance, past and present activities (Gil et al, 2001), which are included in the Measure of Self. ‘Thinking about the future’ was considered and discarded because it would add extra burden time-wise, and would be difficult to interpret as there are few studies for comparison.

ii) No action required.

iii) It was not feasible for practical reasons to include wider aspects of self-expression as part of the Measure of Self. However, embodiment was used to create the observational framework.

To summarise, the key challenges were:

- How to capture the interconnectedness of the multiple aspects of self in a single measure.
- How to ask/prompt questions in a standardised way that enabled all participants, especially those with more severe dementia to respond, whilst being person-centred and responsive to the abilities of all participants.
- Finding ways of observing responses by people who had limited verbal communication abilities. Their responses had to be meaningful in terms

of what they represented, whilst being 'objective', i.e. able to be converted into numbers so that data could be analysed statistically.

These general points were considered when analysing the expert advisors' specific opinions about each of the 16 measurement tools that had been sent to them. Their responses are summarised in Table 4.4, see also Appendix VI for more detailed presentation of their responses.

Table 4.4: Expert Opinions For and Against Each Measurement Tool

Measurement Tool	For	Against
The Autobiographical Memory Interview (AMI, Kopelman et al, 1989)	CR: Useful Episodicity Rating Scale as outcome measure. Includes assessment of semantic as well as episodic events. Could be adapted to use visual or audio prompts for recall.	CR: Long task. Restrictive because it depends on generalised events that not everyone has experienced, e.g. getting married. SS: Participants are expected to answer questions on command, may remember details at a later date – only get a snapshot. Participant may also talk about something unrelated, but that they have remembered, so difficult to score.
AMI Extended (AMI-E, Naylor & Clare, 2008))	CR: More probes than AMI so better chance for participants to recall memories.	CR: As above, makes assumptions about what people's lives are like. If they haven't experienced specific events, may score unfairly low.
The Autobiographical Interview (AI, Levine et al, 2002)		CR: Requires training to administer. Probes may not elicit memories that are significant for identifying self, so not really a measure of self. Series of instructions may be difficult for people with short-term memory impairment.
The Twenty Statements Test (TST, Kuhn &		

McPartland, 1954) **The IMAGE Test** (Eustache et al, 2013) **The Oral I-AM Test** (Eustache et al, 2013) **The 3-I Test** (Duval et al, 2012) **The Tennessee Self-Concept Scale** (TSCS, Fitts, 1965) **The Self and Identity in Dementia Questionnaire**	CR: Possible to adapt to Ten Statements. More specifically a 'self' test. Useful for people with dementia. Measures of semantic autobiographical memory. Open-ended so people can say what is important to them. Can use pictures as cues. CR: Similar to the Twenty Statements Test because of open-ended questions. CR: Taps into memories that are important to a person, i.e. self-knowledge. CR: Can be made 'dementia friendly'. Can be informative because of the sub-scores. Can use pictures as prompts.	CR: Generating 20 statements is challenging. Asking people to simply point at pictures that they like (if used as cues) may not tap into what is idiosyncratic to them. Need to think carefully about how to ask 'Who are you?' and how participants respond. Could give examples as prompts, but need to say same to everyone. CR: Measure of how 'happy' or 'sad' people are at particular times – could depend on social circumstances rather than individual differences. Does saying you have a particular characteristic "some of the time" mean you have a high or low sense of self? Specific questions that could be challenging for people with dementia if they depend on complex memories CR: Difficult to use pictures – how can they be rated 'some of the time'? CR: Difficult to adapt using pictures as prompts. Future thinking not part of the Model of self diagram. Difficult to score. SS: Questions are situational – social component affects how people respond to questions.

(SIDQ, Cohen-Mansfield et al, 2000) **The Creative Personalities Scale** (Gough, 1979) **The Questionnaire of Self Representation** (QSR, Duval et al, 2013) **The Sense of Belonging Scale** (Hoffmann et al, 2002-3) **The Life Orientation Task** (LOT, Scheier & Carver, 1985) **The Rosenberg Self-Esteem Scale** (Rosenberg, 1965) **The Physical Self-Concept Scale for Older**	CR: Brings in social element, traits and semantic and autobiographical memories, so holistic view of self. Can use pictures as cues. Many of the activities in the scale are relevant to people in the older age group. CR: Covers memory, social, personality so holistic.	CR: Does not liking a particular activity suggest a strong or weak sense of self? CR: Being creative is only one possible attribute of self so measure is of limited value. CR: May be difficult for people with dementia because statements depend on memories. Some questions are difficult, e.g. 'I am generally attentive to my inner feelings'. If a participant is unsure about a question, s/he may choose midpoint unfairly suggesting a weak sense of self. SS: Cannot assume that people with dementia are part of, or feel part of a group. CR: Used with people with AD but difficult for them to remember scores for responding. CR: The new measure is not about self-esteem. SS: Allows researcher to know *what* a person feels but not *why.* Starting point for conversation rather than end in itself. Need more nuanced rating scale.

Adults (PSSOA, Hu & Lu, 2013)		CR: More like a wellbeing scale. People tend to talk about roles and social relationships as enduring aspects of identity, rather than physical things.

v) Eliminating measures

Table 4.4 enable comparison of the experts' views for and against each measure and it is clear to see that for 7 of them there were no points in favour of using them. Considering points made against the measures, four (AMI, AMI-E, AI and QSR) were considered to be largely reliant on effortful recall of autobiographical memories which would be challenging for people with more advanced cognitive impairment. Also, the instructions for completing the interviews were complex so would be difficult for this group to follow. Therefore, these measures were discarded. Five measures (Creative Personalities Scale, Sense of Belonging Scale, LOT, Rosenberg Self-esteem Scale and the PSSOA) were considered to relate only to specific aspects of self (such as creativity and self-esteem) so would be of limited value to the Measure of Self, or had complicated response scales that would be difficult for participants to remember. The IMAGE test was thought to contain questions that were too challenging for people with more severe dementia. The Oral I-AM Test and the 3-I Test cover all aspects of self in the Model of Self (see Table 4.3) but they were discarded because the experts noted that the Oral I-AM would be difficult to adapt to using visual images as prompts, and the 3-I Test incorporated future thinking that had not been included as a component of the Model of Self.

Thus, three measures were retained and these were chosen to provide the basis of the Measure of Self, namely the Twenty Statements Test, the Tennessee Self-concept Scale and the Self and Identity in Dementia Questionnaire. Taken together these measures covered all the aspects shown in the proposed new Model of Self, and the administration methods could be adapted to use visual and auditory stimuli rather than only written or verbal instructions.

4.2.3 Creating the first version of the Measure of Self

The following section outlines how the elements of the new measure were determined, specifically how to adapt the questions and what sort of stimuli to use to elicit responses, and how to group and present the stimuli. Methods of scoring were considered, and ways of observing responses of people who had difficulty expressing themselves verbally.

Deciding on the content of the Measure of Self

The aim at this stage was to adapt elements of the three tests to create a tool suitable for people with cognitive impairment by providing stimuli that would enable participants to choose between, rather than generate, self-statements themselves. It was decided that this could be done by creating stimuli that would allow participants to indicate which aspects of self they identified with, i.e. were most like them. It was envisaged that the stimuli could consist of photographic images with words printed above the image such as 'I am a gardener'. To develop the visual stimuli, the following steps were taken:

i) Deciding on the nature of the stimuli sets.

ii) Deciding on the nature of the stimuli (e.g. visual, auditory, physical objects).

iii) Locating the stimuli.

iv) Deciding on methods of responding to the stimuli.

The nature of the sets of stimuli

The sets of stimuli and items within them were informed by several sources. They were initially informed by 'domains of identity' used in the Self and Identity in Dementia Questionnaire (Cohen-Mansfield et al, 2000), namely family relationships, work role/s, leisure activities, and identity related to group membership, traits and achievements. Additionally, Rathbone and Moulin (2017) had published a 'self-image database' of responses to 'I am…' statements, divided into 'categories' (such as active, appearance, occupation) and 'specifics' (such as walking, tall or short, teacher). This database, along with the domains of identity from the Self and Identity in Dementia Questionnaire, provided the basis for three sets of stimuli for the Measure of Self: 'Activities', 'Relationships and Occupations', and 'Traits and Physical

Characteristics'. As the database also provided frequencies of generation of specific statements and ages of respondents, it was possible to identify statements to use as stimuli that were more commonly given by middle-aged and older people. However, there was not a large enough number of results from older people (over 65 years) to restrict statements to this age group, so statements with high frequencies in the middle-age group (40 to 65 years) were also used to guide the choice of stimuli. Statements from the 100-item Tennessee Self Concept Scale (Jamaludi et al, 2009) were compared with this list to double check the relevance of self-images, and this also provided suggestions for others that were not included in the database. Additionally, in order to produce a wide range of work roles and occupations, the Standard Occupational Classification (2000) document was consulted. Table 4.5 provides an overview of the self-images taken from the database, self-concept scales and classifications described above, that were initially considered for representation as stimuli.

Table 4.5: List of Possible Self-related Statements that were Considered for the Measure of Self

Activities	Relationships & Occupations		Traits and Physical Characteristics	
Animal lover	Brother	Academic	Always busy	Height
Artistic	Daughter	Accountant	Anxious	Build
Care for others	Father	Air hostess	Calm	Hair colour
Creative crafts	Grandfather	Ambulance driver	Clever	Wrinkled skin
Dancing	Grandmother	Antique dealer	Confused	Body is stiff
Cooking	Husband	Architect	Curious	Able to walk a long way
Eating out	Wife	Baker	Easy-going	Get tired easily
Gardening	Mother	Barmaid/man	Elegant	Clean house without help
Going to cinema	Sister	Builder	Forgetful	
Going to theatre	Son	Business man	Frightened	
Hobbies		Carpenter	Funny	
Household chores		Chef/cook	Good manners	
Listening to music		Children's nurse	Happy	
Outdoor activities		Cleaner	Healthy	
Physical exercise		Dentist	Helpful	
Playing sports		Doctor	Honest	
Politics		Driver	Interested in others	
Puzzles and games		Engineer	Lazy	
Reading		Estate agent	Lonely	
Religious activities		Farmer	Musical	
Shopping		Female executive	Punctual	
Singing		Fireman	Shy	
		Hairdresser	Thoughtful	
		Lab Technician	Worried	
		Lawyer		
		Miner		

Socialising Spending time with family Travel for leisure Volunteering Walking and jogging Walking pets Watching sport Watching television		Nurse Office worker PE teacher Plumber Policeman/woman Receptionist Removal man Scientist Seamstress Secretary Shop assistant Stockman Surveyor Tailor Teacher Waiter/waitress Welder		

The three sets of stimuli (Traits and Characteristics, Relationships and Occupations, and Activities) were divided into 10 subsets:

1. Traits, e.g. honest
2. Physical characteristic, e.g. fair haired
3. Family roles, e.g. wife/husband
4. Occupations, e.g. engineer
5. Sports, e.g. football
6. Hobbies, e.g. model-making
7. Outdoor activities, e.g. walking
8. Indoor activities, e.g. reading
9. Social activities, e.g. dancing
10. Abstract, e.g. artistic

The initial numbers of stimuli for each set were 27 for ‘Traits and Physical Characteristics’ and 44 for ‘Activities. ‘Relationships and Occupations’ consisted of a set for male and a set for female participants; the male set consisted of 52 stimuli, and the female set 41 stimuli. As far as possible occupations were matched, e.g. postman/postwoman, hairdresser/barber, but for some occupations, such as miner and welder, there was no female equivalent for the time periods relevant to the current participants, causing the numbers of stimuli to be unequal. Also, a compromise had to be made between offering a wide range of occupations for participants to choose from without presenting so many that they became disinterested. Appendix VII lists some of the

occupations presented in the Standard Occupational Classification document and demonstrates that covering the whole range would have been impractical in terms of the number of stimuli required, and the time taken to present all the stimuli to participants. Eleven categories of occupation are presented in the table, with between 6 and 20 specific occupations in each category. It was, however, necessary to keep to the methodological requirement of providing cues for participants, rather than simply asking them to say what their occupation/occupations had been. Therefore, to reduce the number of stimuli, specific occupations were merged into one type where possible (e.g. 'driver' for bus, train and coach driver, and 'shop assistant' for all types of shop worker). Appendix VIII contains tables of stimuli represented in the Measure of Self.

Choosing stimuli: sounds, objects or images?

All three expert advisors commented on the importance of presenting appropriate stimuli, rather than words alone, to act as cues for eliciting opinions from the participants about aspects of themselves. For example, Pia Kontos described occasions when a religious book and a religious song elicited powerful memories in people with severe dementia. Therefore, artefacts, music and images were considered as stimuli, for example the sound of a telephone ringing with the picture of a telephone with a dial, or part of a relevant song with the picture of a vinyl record. However, ultimately only images were presented as this was the most practical option in terms of collecting a large enough number of stimuli, and ensuring simplicity of administration. Furthermore, using sounds and objects would have introduced more variables and it would not have been possible to determine if it was the object and/or sound and/or image that was eliciting a response if one occurred.

Therefore, the next phase of development was to search the Internet for freely available images that would represent all of the statements of self required. For each statement both photographic and drawn (or cartoon) versions were sought, so that a decision could be made about using either photographs or drawings, or both types of image. The images were accessed via 'Creative Commons' websites (https://search.creativecommons.org/), filtering for 'non-commercial reuse with modification'. It was not possible to find photographic or drawn versions for all the statements of self listed, for example 'interested in others' was difficult to represent visually, similarly the physical characteristics of

‘walk a long way’, ‘get tired easily’, ‘clean house without help’. To accommodate this, these characteristics were represented in the ‘Activities’ set as ‘I am a walker’, and ‘I am good at household chores’ and in the ‘Traits and Physical Characteristics set as ‘I am lazy’. Another consideration was that the images should relate to the time periods relevant to when participants would have performed the activities or been employed, and coincide with the reminiscence bump era of the participants. For example, 1950s and 1960s dance halls would be recognised more easily than modern nightclubs, similarly a secretary using a typewriter rather than a person sitting in front of a computer. However, this also restricted the option of the researcher using photographs taken by herself because such pictures would be too contemporary and might not be memorable for older people.

Consulting service users about selection of stimuli

Service users were consulted again at this stage primarily to ensure face validity of the stimuli in terms of the most appropriate ways of presenting them to participants with dementia. A new group of service users (clients attending a day care centre) were consulted in order to gain views about what types of stimuli to use and how they should be presented to participants, specifically:

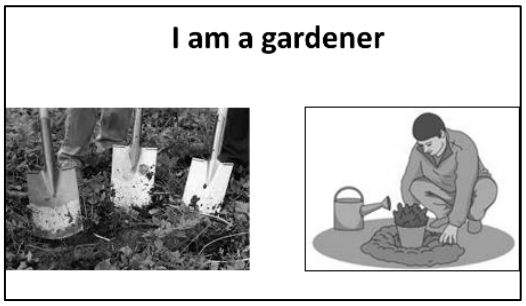
- Whether to present a single image to convey a concept or whether to present two images.
- Whether to present photographs or drawings/cartoons.
- Whether to present colour or black and white images.

Examples of each mode of presentation were shown in a display folder, some of the images are shown below.

single image

double image

colour photo v. cartoon



black and white photo v. cartoon

The consensus of opinion was that photographs were preferable to drawings or cartoons, because photographs are more familiar and therefore meaningful to older people. Single images were preferred to double because one image was sufficient to convey the concept, and colour to black and white, because colour images were more true to life. Feedback suggested that the core activity, trait or relationship should be the central focus of the image, with minimal background as this could distract from the construct the image was intended to display.

Choice of response

The requirements for the stimuli were that they had to be presented clearly, be easily understood and not give so many choices that participants became confused. The most commonly used methods for responding to psychometric tests used by cognitive psychologists which were considered for the Measure of Self are described below:

***Dichotomous Items*:** these are questions that require a 'yes' or 'no', or 'true' or 'false' response, that can be assigned values of 0 or 1, or 1 or 2. These are the simplest ways of extracting data and have been shown to be reliable in, for example, personality inventories (Kline, 2000). A third 'don't know' response may also be used, but Kline suggests that this middle category may be too tempting for participants who find it difficult to make definite choices, so three-item scales may be less valid than two-item scales.

***Likert-type Rating Scales*:** Likert scales commonly present a series of 4,5,7 or 9 responses, ranging from such choices as 'always' to 'never', or 'agree strongly' to 'disagree strongly' (e.g. Duval et al, 2012). There are arguments for and against each range of choices; a small number can result in poor discrimination, but too many can lead to fatigue, confusion and frustration (Lehane & Savage, 2013). Also, there is a tendency for participants not to

choose extremes, and a middle category may encourage participants to not make a decision for or against a statement (Kline, 2000).

***Forced Choice Items*:** participants must select a response that provides a specific answer to a question, for example being asked to choose a liking for tea, coffee or hot chocolate, which could be scored 1, 2, or 3. However, these may not be truly informative because once one item is chosen another cannot be selected, and participants may be forced to choose an answer that may not actually be true for them.

Visual analogue scale (VAG, Stern et al, 1997). The VAG consists of a horizontal or vertical line, anchored at each end by extreme representations of the variable being considered, e.g. extremely sad to extremely happy. The participant indicates by drawing a mark on the line his or her position on the scale.

After considering each of these options it was decided to have three choices of response: “Just like me”, “A bit like me” and “Not at all like me” for the following reasons. Addis and Tippet (2004) asked participants with mild Alzheimer’s disease to choose their responses to the Tennessee Self Concept Scale from a 5-point Likert Scale in order to be able to assess quality and positivity/negativity of identity. However, considering advice given by our expert advisors, it was agreed that a 5-point scale was likely to be too demanding for people with dementia. A dichotomous scale would be less demanding, but would not enable analysis of the desired outcome measures of strength, complexity and quality of identity (see section 4.3.4). Using the VAG would mean displaying two images for each stimuli (one at each end of the line); as stated above, the consensus from the group of experts by experience was that single images would be preferable. Therefore, it was decided that the VAG would not be used, and the three ‘like me’ response options were chosen, to provide the best compromise.

Choice of observational methods for collecting behavioural data

This project intended to develop a measure that did not require verbal responses, therefore the aim of the project was to develop an observational framework with which to capture responses of participants who were unable to say these explicitly, i.e. which of the ‘like me’ statements were appropriate for them, or indicating their ‘level of interest’ in the stimuli. If a participant could not

say or show where to position a stimulus it was proposed that their facial expressions, bodily gestures or interaction with the stimulus might indicate how interested they were in the stimulus and thus how meaningful it was for them. It was envisaged that a checklist or 'framework' of behaviours would be designed to code actions as aligning to 'Just like me', 'A bit like me' or 'Not at all like me'. The reasoning behind this is that these expressions and gestures are behaviours which are learnt and become 'embodied', so that they happen automatically without conscious awareness throughout a person's lifespan (see also Chapter 2, section 2.2.9). Studies have shown that people with advanced dementia are able to express a range of emotions, such as furrowing of the brow (bewilderment), fidgeting (anxiety), exasperated voice tone (frustration) as well as smiling and laughter to display happiness (Mayhew et al, 2001). It was proposed that these actions could indicate participants' responses to the Measure of Self stimuli and thus how 'like them' they thought each stimuli was.

The most appropriate method for observing behaviours was determined by investigating a number of established observational methods, namely behavioural analysis, functional analysis, and interaction analysis (see Appendix IX for more detail and examples of studies using these methods). Behavioural analysis (Oyebode et al, 2008) was chosen as the most appropriate method because it has been used successfully with people with moderate Alzheimer's disease who found it difficult to complete traditional questionnaires. Functional analysis (Beaton et al, 2006) was not appropriate for this project because it is intended to investigate *why* behaviours occur, specifically behaviours that are judged as 'bizarre' or undesirable. Interactional analysis (Jordan & Henderson,1995) was also not appropriate because it is a method for investigating interaction of human beings with each other.

To generate a set of potential observable items that would allow accurate identification of non-verbal responses, the items within a number of observational tools that had been used with people with dementia were considered: the 6-item Philadelphia Geriatric Centre Rating Scale (Lawton et al, 1996), the Greater Cincinnati Chapter Well-being Tool (Sauer et al, 2014), and the Positive Response Schedule for Severe Dementia, (Perrin, 1997; see also Appendix X for details of these measures). Rather than choose only one of these instruments to use, the behaviours included in each of them were listed

and from this a smaller number of observable behaviours was generated that were thought to be most relevant to the Measure of Self. Table 4.6 lists these behaviours and defines them as indicators of engagement, i.e. suggesting interest in an item, and neutral indicators suggesting lack of interest.

Table 4.6: Observational Behaviours Demonstrating Engagement or Neutrality

Type of response

Engaged	Neutral
Eyes follow object	Passivity
Eyes follow person	Staring into space
Visual scanning	Leaving activity area
Facial or motor feedback	Shrugs shoulders
Maintain eye contact	Sighing
Turn towards object	Asks what is happening
Turn towards person	Physical restlessness
Conversation	Mumbling
Seeks approval	
Expression of assertiveness	
Sustained attention	
Comfortable position	
Smooth facial muscles	
Lack of tension	
Slow movements	
Smiling	
Laughing	
Stroking	
Touching with approach	
Nodding	
Singing	
Humming	
Arm or hand reaching out	
Open arm gesture	
Eyes crinkled	
Body response	

It was proposed that the testing sessions during the pilot study would be video-recorded (when participants consented to this). Evidence of embodied behaviours would be looked for and noted by the researcher with the purpose of developing a coding framework equivalent to “Just like me”, “A bit like me” and “Not at all like me”. Table 4.6 formed the starting point for analysis of the video

recordings made during the pilot study interviews which will be reported fully in section 4.6.

4.3 Pilot study: Procedure

The overall aim of the pilot study was to ensure that the content and outcome measures of the new Measure of Self was suitable for use with people with dementia and that the methods of administration were also suitable for people with dementia, and that it could potentially be used easily by other researchers and practitioners without requiring extensive training.

This was to be achieved by:

1. Refining, if necessary, the numbers of items shown in the three sets of images forming the Measure of Self, i.e. i) 'Activities', ii) 'Traits and Physical Characteristics' and iii) 'Relationships and Occupations'.
2. Clarifying the optimum numbers of images to be shown for each item, i.e. one image on one side (shown first) and four images on reverse side. The four images were intended to act as additional prompts by being shown to participants when they were unable to respond to the single image on the front of the stimulus.
3. Refining if necessary the instructions for participants.
4. Checking the effectiveness of the three 'like me' responses, i.e. 'Just like me', 'A bit like me'. 'Not at all like me'.
5. Establishing a framework of observed behaviours for participants with limited vocabulary.
6. To produce preliminary findings about self in dementia.

The following sections outline the preliminary procedures that were undertaken before field testing could begin, followed by accounts of the testing in practice.

4.3.1 Stage 3: Obtaining ethical approval for the pilot study

The ethical approval process required review by two committees, the University of Bradford Ethical Review Panel and a local NHS HRA Research Ethics Committee. The study was approved by the University review panel and was then sent to Yorkshire & The Humber-Leeds West Research Ethics Committee. The REC committee requested some amendments to the original proposal,

specifically that people without capacity to consent should not be recruited for the study. The protocol sent to the committees can be found in Appendix XI with full details of the ethical considerations and consent procedures. Approval was agreed (16/YH/0473, IRAS project ID: 190354, see Appendix XII).

4.3.2 Stage 3: Recruitment of participants for pilot study

Twenty participants were recruited. This number was determined by following the recommendation of Watson (2013) for a study of this kind intended to demonstrate content validity of a questionnaire. Inclusion criteria were:

- Adults with a diagnosis of probable dementia who had capacity to make an informed choice to participate in the study.
- English-speaking and able to understand spoken and written words, with hearing aids if necessary.
- Vision (with glasses) needed to be sufficient to clearly view images and words printed on A4 paper.

The exclusion criterion was people who lacked capacity to consent.

Prospective participants were identified and recruited by the researcher who contacted dementia support groups in Bradford and Leeds via Bradford Alzheimer's Society, Leeds Alzheimer's Society, Bradford and District Age Concern and Bradford Senior Power. Additional contact was made with social groups and day care centres for older people in Bradford and Leeds. The groups included ones that were held monthly, weekly and every two weeks, focusing on activities such as reminiscence, singing for the brain and varied social activities. The researcher visited managers from these groups and organisations, giving them posters and information leaflets to distribute to individuals who they thought would be interested in taking part. Inclusion and exclusion criteria were explained to the managers and organisers. People who wished to find out more about the study were asked to contact the researcher directly (contact details were on the posters and leaflets), ask a relative or friend to do this for them, or tell staff or managers of their interest. Approximately 24 to 48 hours later the researcher contacted the support groups and care homes again to determine whether any attendees or residents had expressed an interest, and if so, arranged to visit the group in person to approach prospective participants personally and provide further information. Alternatively, names of

individuals who were interested were passed on to the researcher who contacted them by telephone in order to discuss the purpose and requirements of the study and arrange times to visit participants in their own homes or in support group locations.

Eighteen support groups and organisations were visited by the researcher, resulting in the recruitment of 20 participants (9 female), age range 66 to 93 years (mean = 77.9. SD = 7.2). Two participants were recruited from a weekly service users group, three from a monthly support group run by the Alzheimer's Society, seven from monthly reminiscence focused groups, three from a monthly singing group, four from general groups for older people held weekly, and one was recruited after the researcher visited a care home. Before confirming that prospective participants wished to take part, the researcher gave them an information sheet describing the study (Appendix XIII). As well as details of the study, and what was required of participants, ethical requirements such as confidentiality, right to withdraw and who to ask for further information were stated. The researcher advised participants that they could keep the information sheet for a day or more, to show to family or friends if they wished, to help them consider whether or not to take part in the study. However, all participants were happy to continue with the interview during the initial visit, and the researcher asked them to sign a consent form (Appendix XIV). If a participant had difficulties reading and/or writing, the researcher read through the consent form with them before assisting them to complete the form. There were two versions of the form; one with text only and one with pictures and fewer words (Appendix XIV). The researcher asked the participants which they preferred to look at and/or keep.

The majority of participants did not have a specific diagnosis of dementia (n= 12). Diagnoses that were given were dementia (n=4) mixed dementia (n=1), Alzheimer's disease (n=1) vascular dementia (n=1) and Lewy Body dementia (n=1). Nine participants were taking dementia related medication. One participant lived with his spouse in a care home, eleven lived alone in their own homes, and eight lived with a spouse or live-in carer, in their own homes. Written informed consent was obtained from all participants, and 19 consented to being video recorded.

Collection of background information and neuropsychological data

Background information was collected before the participants were interviewed, specifically, demographic information consisting of date of birth, gender and level of education, and the FAST Scale of functional abilities (Reisberg, 1988) for participants who were unable or not willing to complete the ACE-III (see below).

The following tests were also conducted after completion of the Measure of Self to provide more detailed information about mood and severity of cognitive functioning related to dementia.

- The 4-item Geriatric Depression Scale (GDS4, Shah et al, 1997)
- The Addenbrooke's Cognitive Examination III (ACE-III, Hseih et al, 2013)

The 4-Item Geriatric Depression Scale (GDS4) is a self-assessment tool that screens for depression in older adults. The test takes about 1 minute to complete with a score of 2 to 4 indicating possible depression. It is known that depression can impair memory (Williams et al, 2007) and that depressed mood may have affected the way participants responded to the Measure of Self, by thinking more negatively about their responses. Fourteen participants completed the GDS4. Seven scored 0 indicating no symptoms of depression, five scored 1 indicating 'uncertain' and five participants scored either 2 or 4, suggesting that they were experiencing symptoms of depression.

Some participants declined to complete the ACE-III and were not asked to give reasons for this; their rest of their data was still used. The ACE-III provided information about the cognitive abilities of the participants measuring memory, attention, language and visuospatial function, which are all pertinent to completing the Measure of Self. Cut-off scores of 82-88 out of 100 (Noone, 2015) indicate suspected dementia. Thirteen participants completed the ACE-III. The range of scores was from 49 to 90, (mean = 62.5, SD = 14.3). One participant scored above the cut-off of 88 but her data were included because her lowest score was for the memory component of the test with full scores for the other components. This suggests that her memory was impaired but other cognitive functions were not impaired.

For participants who did not complete the ACE-III the FAST Scale of functional abilities (Reisberg, 1988) was completed by consulting a relative or carer who knew the participant well. The FAST scale describes 7 stages of dementia

related to physical and cognitive abilities. Stage 1 indicates no cognitive decline, and Stage 7 indicates severe dementia. The FAST scores ranged from 3 to 5, indicating mild to moderately severe cognitive decline.

4.3.3 Study design

The study took the form of one-to-one interviews. Each participant was interviewed on one occasion. All participants were able to go at their own pace and the researcher asked at the end of each phase (see section 4.4.3) if they were happy to continue, or would like a break. Everyone was happy to continue the sessions without a break. The Measure of Self took approximately 30 to 40 minutes to complete. There was an option for the testing to be spread over more than one session, but no participants wished to continue the interview at a later date.

Materials

The materials for the new measure comprised a range of stimuli relating to the multiple aspects of self and, as described in section 4.2.4 above, were divided into 3 sets and 10 subsets:

Set A: ***Activities:*** 6 subsets, with a total of 44 stimuli.

Set B: ***Traits and physical characteristics***: 2 subsets, with a total of 27 stimuli.

Set C: ***Relationships and occupations***: 2 subsets for male and female participants, also with 2 subsets each. When presented to participants, each subset contained up to 13 stimuli, depending on which category of occupation they chose.

Each stimulus consisted of pictures and written statements starting with ‘I am…’ or ‘I was…’ printed in large font (size 32) on laminated sheets of A4 paper, for example ‘I am football fan’; ‘I was a scientist’. The three response cards: ‘Just like me’, ‘A bit like me, ‘and ‘Not at all like me’ were also printed in large font (at least size 56) on laminated cards measuring 21x5 cm. There were images on both sides of the stimuli. The ‘front’ consisted of a single image with the statement above it; the ‘reverse’ consisted of the same statement with 4 different images relating to the statement.

Front of stimulus: **I am a football fan**

Reverse of stimulus: **I am a football fan**

The examples presented above are from the ‘Sports’ subset of the ‘Activities’ set. The ‘Activities’ set consisted of 44 stimuli taken from the database of ‘I am..’ responses (Rathbone and Moulin, 2017), the ‘Traits and Physical Characteristics’ set consisted of 27 stimuli taken from the Tennessee Self-Concept Scale II (Fitts & Warren, 1996). The ‘Relationships and Occupations’ set was initially informed by the ‘Occupation’ and ‘Family membership’ sections of the Self and Identity in Dementia Scale (Cohen-Mansfield et al, 2000), and was divided into two subsets: one for male and one for female participants. There were 5 relationships specified for each gender (e.g. father/mother, brother/sister), and 7 categories of occupation (e.g. professional, skilled trades), with an average of 7 occupations per category, taken from the Standard Occupational Classification 2000 (ONS, 2000). Over the whole of the Measure

of Self each participant was presented with a maximum of 106 stimuli, depending on the number of occupations they were shown.

Answer sheets (see Appendix XX) for the use of the researcher were included for each set of stimuli and phases described in section 4.3.3. Standardised instructions were printed on each sheet so that the researcher gave the same instructions to each participant. Responses were written on the answer sheets, identified by participants' ID numbers only. There were two sets of answer sheets relating to the Matching Phase and the Sorting and Memory Phase. There were answer sheets for each of the three sets of stimuli presented during the Matching phase (Appendix XX); each sheet comprised five columns headed: 'Just like me', 'A bit like me', 'Not at all like me', 'Don't know' and 'Review questions/comments'. A record of each stimulus chosen was written in the relevant column, for example 'mother' in the 'just like me' column. Answers to questions asked during the review phase were written in the 'comments' column.

The answer sheet for the Sorting and Memory Phase (Appendix XX) comprised three columns headed 'Details of memory', 'Prompts' and 'Review questions/comments'. Descriptions expressed by participants were written in the 'Details' column as accurately as possible, including gestures and facial expressions when these were observed by the researcher. These descriptions were augmented when viewing video recordings. Recording the number and types of prompts given by the researcher provided additional information for the Review Phase questions. If a participant talked quickly making it difficult for the researcher to write down all details of a memory the researcher aimed to note features of the memory that were indicative of episodicity, e.g. specific time and place. The Episodicity/Level of Interest score (see section 4.3.4) was also recorded on the 'Sorting and Memory' answer sheet. If a participant talked about a specific person who was identified by name, or a place that identified the participant, the names of people or places were changed when data was recorded for analysis or when written in a report.

4.3.4 Procedure

The administration of the Measure of Self consisted of 6 phases:

1. Practice phase
2. Matching phase

3. Review of Matching phase
4. Sorting and Memories phase
5. Review of Sorting and Memories phase
6. Finishing the interview and debriefing

Phases 2 to 5 were video recorded. If a participant had wished to perform the test over two sessions a suitable division would have been between Phases 3 and 4. Figure 4.2 below illustrates the administration of Phases 2 to 5.

Practice Phase

This phase was intended to show the participants what they would be asked to do and enable the researcher to judge if they would be able to complete the procedure. The 3 response cards labelled 'Just like me', 'A bit like me' and 'Not at all like me' were positioned in front of the participant and the researcher confirmed that the participant was able to read and understand what was printed on each card. Three stimuli (e.g. 'I am a good friend', 'I was a painter', 'I am caring') were given one at a time to the participant to place in front of one of the 'like me' cards according to how like themselves they thought the statements were. The researcher read from an instruction sheet: *"I am going to show you a picture. Do you think this picture is like you? Can you place it in front of the card that describes it best: 'Just like me', 'A bit like me', or 'Not at all like me'?"* Participants either placed the stimuli in front of their chosen response, told the researcher where to place it, or pointed to where it should be placed.

The researcher reminded the participant what to do if necessary by repeating the instructions, and prompting with further standardised questions, such as "Would you say you are a friendly person?" If the participant responded with 'yes' the researcher asked *"Would you say being friendly is 'a bit like you' or 'just like you'?"* If the participant did not respond verbally or did not place the stimulus in front of a response card the researcher observed his or her gestures and facial expressions to judge where the stimulus should be placed, and placed it for the participant. The researcher observed the participant again to judge if this was correct. If a participant was still unsure about what to do, the

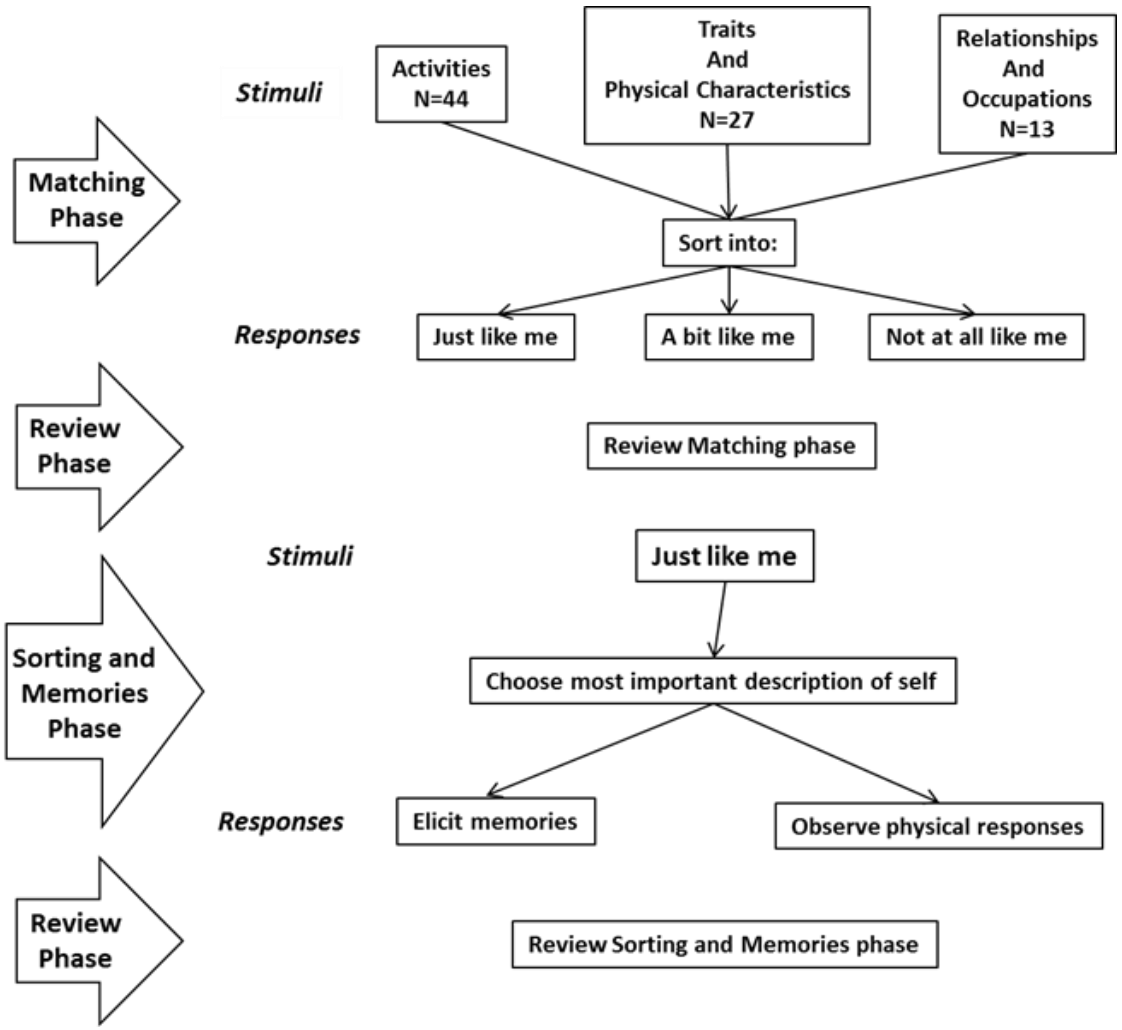


Figure 4.2: Administration of the Measure of Self

researcher repeated the practice procedure. At the end of the practice procedure the researcher asked the participant if he/she was happy to continue with the rest of the interview. All participants were happy to do so.

Matching Phase

This phase required the participant to look at each of the stimuli in turn and place each one under the desired response. Before starting the researcher asked the participant if they were still happy to be video recorded and if the participant agreed to this the researcher started the video recording. A compact HD digital video recorder was used. It was fitted to a tripod placed in front of the participant on a table, on the floor or on a suitable surface nearby. The intention was that the participant should not feel uncomfortable or overly conscious of being recorded.

The interview began by the researcher placing the first set of stimuli on the table next to the participant. The three response cards were in front of the participant.

The researcher handed the participant the stimuli one at a time and read from the instruction sheet*: "I am going to show you a picture. Do you think this picture is like you? Can you place it in front of the card that describes it best: 'Just like me', 'A bit like me', or 'Not at all like me'?"*

The researcher allowed time for the participant to think about his or her response, and to put the item on the table before giving him or her the next stimulus. Prompts were given if necessary to help the participant make a choice, such as *"Can you think of an occasion when you did this/were like this?, and if so, "Was it just like you or a bit like you?"* (Appendix XX)

If a participant was unsure about the meaning of the image on the front of the stimulus, the researcher turned the stimulus over to show four more related images. If a participant was unable to place the stimulus in front of a response card but showed indications of how much like him or her the stimulus was, the researcher placed the stimulus in front of the relevant response card, and asked the participant if this was correct. The researcher observed the participant to check that this was the correct position, for example nodding or smiling. If the participant was still unsure the researcher put the stimulus to one side and categorised it as "Do not know". The procedure continued until all the stimuli in the first set had been considered; the procedure was then repeated for the remaining sets.

Review of Matching Phase

This is the first of two review phases which were intended to identify aspects of the Measure of Self that needed changing or refining, by asking participants the following questions:

- *In the task we have just completed did you think the instructions were easy to understand?*
- *How well did you think the pictures matched the written statements?*
- *Was it easier to look at one picture or four pictures?* (if the participant had looked at pictures on the reverse of the stimuli)

Sorting and Memory Phase

The purpose of this phase was to determine which one out of all the stimuli chosen as 'Just like me' a participant considered to be the most important to him or herself, and then establish whether this stimulus triggered a significant autobiographical memory (semantic or episodic) for the participant.

When the participant was ready to continue all the stimuli chosen as 'Just like me' were selected and two stimuli from the top of the pile were given to the participant who was asked to choose which one was most like him/her. If the participant was unsure how to choose between the two the researcher asked questions depending on which set (Activities, Traits etc.) the stimuli were part of. Either *"If you had to choose between one of these activities which one would you like to do the most?"* or *"Which of these describes you the best?"*

The researcher kept hold of the stimulus that the participant chose as most like him/her and put the discarded stimulus to one side. The researcher took the next stimulus from the 'Just like me' pile and again asked the participant to choose between the two stimuli. The 'most like' stimulus was again retained and the discarded one put to one side. This procedure continued until all the 'Just like me' stimuli had been studied and a single stimulus remained that was considered to be the most important self-description. If the participant was unable to complete this sorting phase, the researcher finished the interview.

When the most important stimulus had been chosen the researcher read questions relevant to the stimulus to act as prompts, with reference to the Autobiographical Memory Interview (Kopelman et al, 1989):

- *Please can you look at this picture again? Can you tell me about a memory you have about being… [whatever the statement says]?*
- *Please try and tell me all the things you remember about it.*
- *Can you tell me a little more about it?*

If a participant was unsure, the researcher showed him/her the four pictures on the reverse of the chosen stimulus and allowed the participant to respond to the pictures.

Review of Sorting and Memory Phase

This review phase again identified whether there were aspects of the Measure of Self that needed changing. Participants were asked the following questions:

- *What did you think about choosing between pictures two at a time?*
- *Did the pictures you chose help to bring back memories?*
- *Did the questions I asked help to bring back memories?*

Finishing the interview and debriefing

The researcher spent a few minutes at the end of the interview talking to and thanking the participant, and encouraging him or her to ask questions if he or she wished. The researcher also asked the participants if they were still happy for the video recording to be retained. If not, the researcher would have deleted the recording immediately, but none of the participants asked for this to happen.

4.3.4 Scoring the Measure of Self

The Measure of Self was intended to yield scores relating to:

i) Strength, complexity and quality of self (with reference to Addis & Tippet, 2004; Kuhn & McPartland 1954; Rathbone & Moulin, 2014)

ii) Episodicity Score for memories recalled by participants without verbal impairment (with reference to Kopelman et al, 1989)

iii) Level of Interest scoring framework for participants with verbal impairment (with reference to Klippi, 2015; Hyden & Peolsson, 2002; Mayhew et al, 2001)

Strength of Self

Strength of self was measured by the total numbers of 'Just like me' and 'Not at all like me' responses across all sets of stimuli. Observable behaviours were also noted from the video recordings and used to create the Observational Framework; findings are presented below.

Strength of Self scores were expressed as percentages because participants were presented with differing numbers of stimuli for the 'Occupations' subset. A high percentage suggests a strong sense of self, thus the maximum score for strength of self is 100%.

Complexity of Self

Complexity of self was indicated by the number of subsets within the 'Just like me' category of response. A more complex sense of self was indicated when a high number of subsets was represented as 'Just like me'. Scores were from 0 to 10 because there are ten subsets.

Quality of Self

Quality of Self was related to the concrete and abstract nature of the stimuli; concrete statements referred to statuses and classes that were well defined such as 'husband', 'gardener' and 'teacher'. Abstract statements included attitudes and traits such as 'happy', 'clever' and 'thin'. Abstract statements are considered to require reflective thinking (Gallagher, 2000) and suggest a higher quality sense of self than concrete statements that come to mind quickly. The stimuli comprised 33 abstract statements and 67 concrete statements; Quality of Self was specified by calculating the percentage of total statements chosen as 'Just like me' that were abstract statements, with a maximum score of 100%.

Episodicity Scores

When a participant talked about things that he or she remembered related to the stimulus chosen as being most important the researcher recorded these in writing as accurately as possible. These memories were scored according to the Episodicity Rating Scale (Kopelman et al, 1998) which rates the descriptive richness of the memories in terms of specificity of time and place.

Each account was given a score ranging from 0 to 3, all the examples below, taken from Kopelman et al (1998) relate to participants' first jobs:

0: A factual memory or statement, no personal details. Example: *"I worked at a shorthand typing college. It was very well run."*

1: A vague personal memory, no specific details. Example: *"I used to do a lot of paperwork. I thought it was boring."*

2: A personal memory but generalised rather than specific in time and place. Example*: "I played a lot of cricket for the works' team. I scored a century one year. We used to travel to places in London."*

3: A detailed memory occurring at a specified time and place, or with specific people. Example*: "We had a day out in London in one of the hotels. They took us by car from Peckham about 6.00 pm to a big hotel in central London. There*

was a dinner and a big speech. I sat next to a friend called Nellie. I was aged 18 at the time. We came home at 3.00 in the morning."

Total scores for each participant ranged from 0 to 3.

Observational Score: Level of Interest

The researcher noted the reactions of participants during the memory phase, and video recordings were viewed afterwards to analyse behaviours in more detail. Analysis of gestures such as pointing, direction of gaze, fidgeting, smiling etc. were used to produce a 4-point scale to correspond with the values of the Episodicity Rating Scale:

0: No interest shown

1: Looking at pictures, showing interest but no signs of recognition.

2: Looking at pictures, nodding, but no movements or sounds related to the images.

3: Looking at pictures, pointing or touching them and own body, smiling, acting out movements related to the images.

Total scores for each participant ranged from 0 to 3.

4.4 Results

Nineteen out of the 20 participants completed all phases of the Measure of Self. The participant who was unable to complete the full test stopped after the Matching Phase because of tiredness, but her data up to that point has been included in the analysis. All participants were able to perform the Measure of Self with no difficulty, except in the case of the one person who was fatigued, and all understood the processes of choosing between the 'like me' responses. All were highly engaged with the stimuli, frequently commenting on those that they considered 'Not at all like me' as well as those chosen as 'Just like me'.

The following sections will report the results of each outcome measure. Statistical analysis was performed using IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp.

Strength of Self

Figure 4.3 illustrates the scores for Strength of Self, i.e. the totals of 'Just like me' plus 'Not at all like me' responses, expressed as percentages. 'A bit like me' responses are also included in the chart. Strength of Self Scores ranged from 68.9% to 97.2% (mean = 82.4%, SD = 7.4), and 'A bit like me' scores

ranged from 2.8% to 31.1% (mean = 17.5%, SD= 7.3). All Strength of Self scores were high, showing that all participants had definite ideas about what contributes to their sense of self and what does not contribute to it.

Figure 4.3 Strength of Self Scores

Figure 4.4 illustrates the proportions of 'Just like me', 'A bit like me' and 'Not at all like me' responses, demonstrating that the 'Just like me' and the 'Not at all like me' were chosen approximately equally.

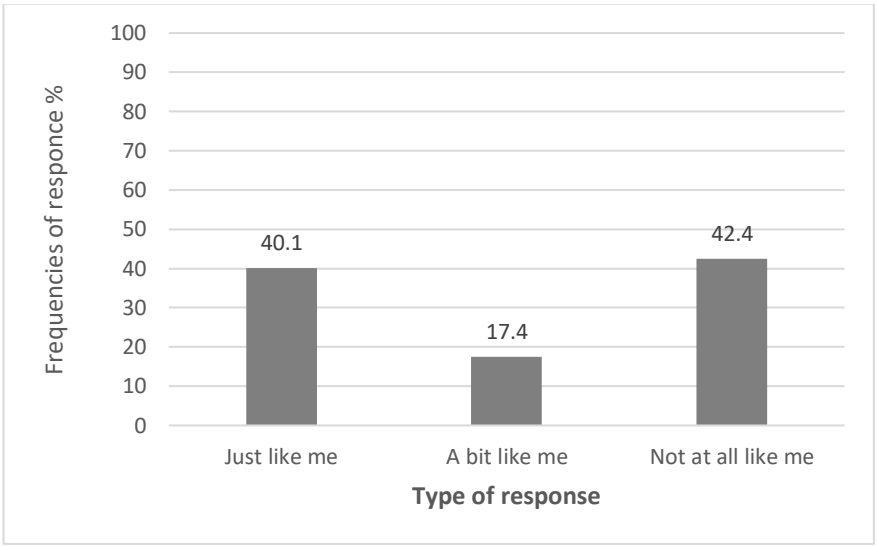


Figure 4.4 Frequencies of Each Type of Response

Complexity of Self

Figure 4.5 demonstrates the range of aspects of self chosen which was from 7 to 10, (mean = 8.4, SD = .82).

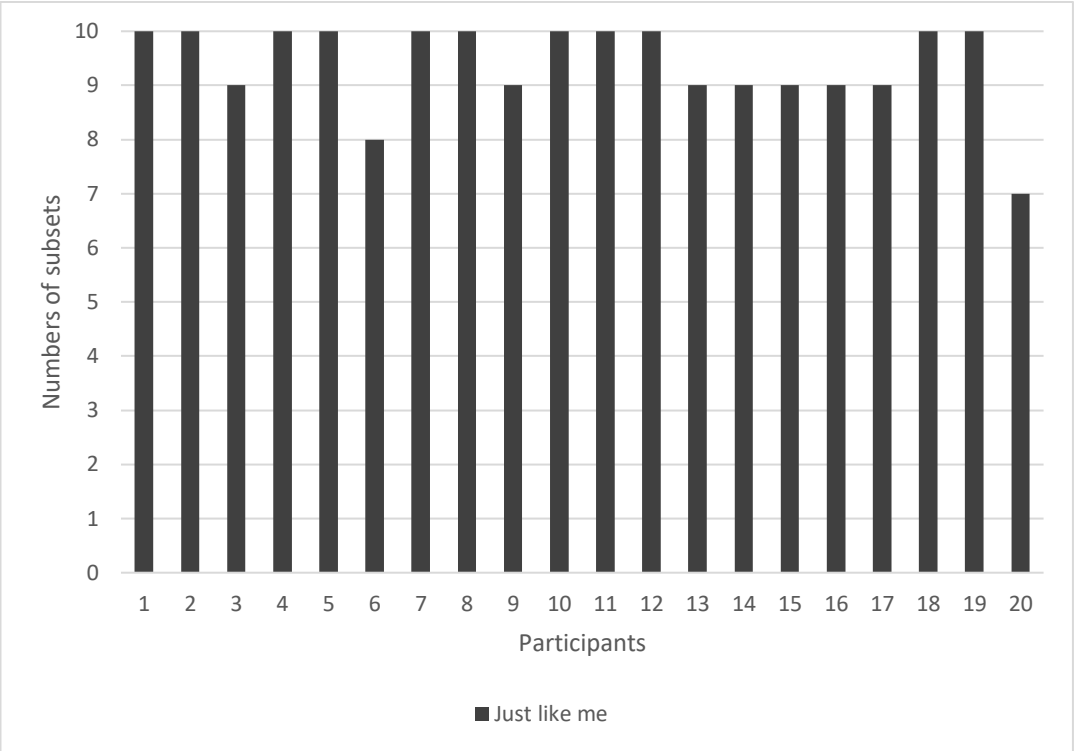


Figure 4.5 Complexity of Self Scores

The scores of 7 to10 for the 'Just like me' responses show that all the participants chose aspects of their selves from at least 7 of the 10 subcategories presented to them, demonstrating that they all had a sense of self that was multifaceted.

Quality of Self

Figure 4.6 illustrates that there was a wide variation in the Quality of Self scores ranging from 22.7% to 50% (mean = 38.3%, SD = 8). This shows that all participants were able to recognise some aspects of themselves that were abstract.

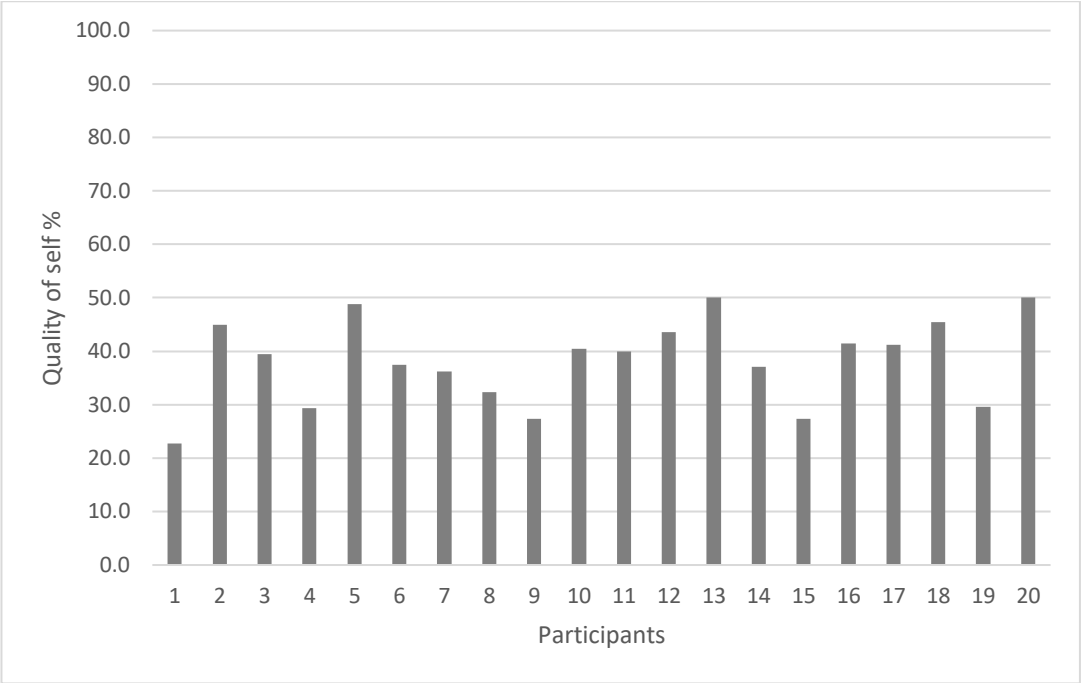


Figure 4.6 Quality of Self Scores

Episodicity Scores

Eighteen of 20 participants were able to talk about the stimulus they chose as most important. One participant finished the Measure of Self before the 'Memory' stage was reached, and one participant said she was unable to think of anything specifically associated with being 'happy' because she was always happy. The researcher used the prompts printed on the answer sheet to encourage the participant to give a detailed memory but the prompts did not help the participant to provide any 'happy' memories. However, during the debriefing part of interview, when no data was recorded, the participant recalled details of her job as a seamstress which she said she remembered when looking at the stimulus.

The numbers of the 4 possible episodicity scores, from 0 (a factual memory or statement, no personal details) through to 3 (a detailed memory occurring at a specified time and place, or with specific people), are shown in figure 4.7.

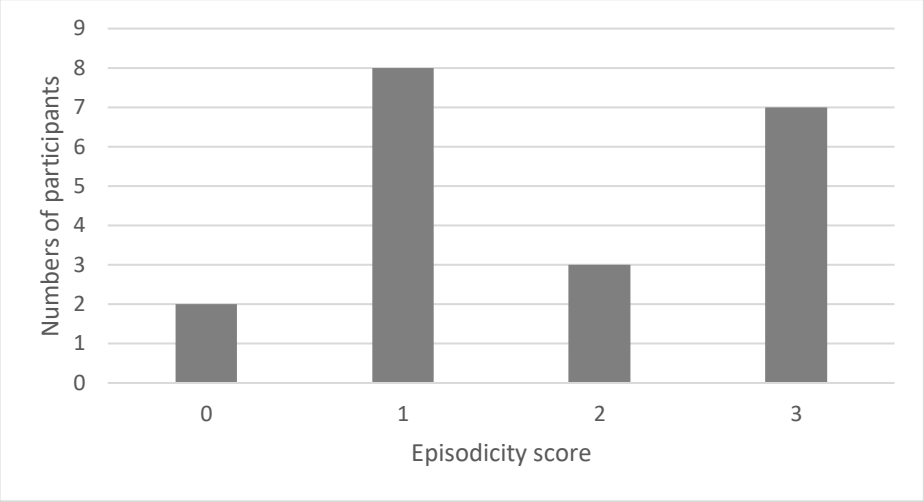


Figure 4.7 Numbers of Participants Scoring Each Episodicity Score

There was a wide range of stimuli chosen as most important. Six participants chose activities (knitting, cricket, caravanning, travel, steam enthusiast, and being religious); 5 participants chose traits (always busy, punctual, happy, honesty, and having good manners) and 9 participants chose family roles (husband, son, sister, and being a family person). Stimuli were categorised as abstract and concrete following Rathbone and Moulin (2014, see also section 4, Sorting and Memories Phase above), who reported that 80% of their participants' most important self statements were concrete (e.g. 'I am a singer', 'I am a daughter'). The results for the Measure of Self are comparable with to these results with 75% of most important stimuli being concrete (activities and family roles).

Regarding the episodicity scores, the results show that 11 participants described vague (score 1) or generalised (score 2) personal memories with no specific details, with 7 participants recalling very detailed memories (score 3).

Examples of responses given to the probe questions listed in section 4.3.3, are given below:

Stimulus: 'I am happy', score = 0

"I'm trying to think….I'm always happy. I can't think of such….you know… Just life makes me happy…meeting new people."

Stimulus: 'I am punctual', score = 1

"When I used to go to school or work, I were always punctual. You had to be. I can't ever remember being not punctual. It would have to be something very serious to not arrive on time."

"I was a poor sleeper, as soon as light was at the windows I'd be waking up, and obviously you've got the clock and things."

Stimulus: 'I am a son', score = 2

***"**My mother used to drive me mad. I used to go and visit. "Do you want a cup of tea son?" "No thanks". "Go on, have a cup of tea". "Alright, thanks, okay, I'll have a cup of tea, thank you". Ten minutes later she'd come out of the kitchen. I'd say "Where's my cup of tea?" She'd say "Do you want a cup of tea?" I'd say, "Forget it", and swear under my breath, you know."*

Stimulus: 'I have good manners', score = 3

"Well, it brings back millions of memories 'cos I've met loads and loads of people and I've always been trying to be helpful and trying to be friendly. I met a lot of people who had no friends at all. So I always used to feel sympathetic to them and try to give out a little bit to enable them to enjoy….so I suppose I've enjoyed that as a major part of my life."

"Well, you might find this bragging, but I remember going to a dinner, and, erm, I had to stand up and make a little speech. And I said, I can't remember the exact words, but it was something like "I just hope you've all enjoyed tonight as much as I have because I've seen all of you smiling, and heard all of you chatting, and it appears to me we've done it right. So I'm speaking on behalf of everybody who's trying to help put this event on, and I'd like to say thank you to everybody, and if anybody disagrees with me, will they come outside", because I want to be producing good manners all the time."

[See Appendix XXI for more memory transcripts.]

Comparing of Measure of Self results with those from a different study

Table 4.7 illustrates that for Strength of Self, the results of the group of participants with dementia who performed the Measure of Self were higher than the results of the group of participants with Alzheimer's disease who performed the Twenty Statements Test (TST) reported by Addis and Tippet (2004). Mean

scores for the TST were 11.68/20 and 18.33/20 respectively, and were converted to percentages for comparison with the Measure of Self. Quality of Self scores (proportions of abstract statements) were almost identical for the dementia groups, both were higher than the control group.

Table 4.7: Comparison of Measure of Self Scores with those reported by Addis and Tippet (2004)

Study	Strength of Self	Quality of Self
Measure of Self	82.4%	38.3%
Addis & Tippet Alzheimer's group	58.4%	37.9%
Addis & Tippet Control Group	91.7%	25.7%

It is difficult to compare the Complexity of Self scores because Addis and Tippet reported their results by numbers of participants who generated specific numbers of subcategories of identity, out of a maximum of 13. For the control group, 13 participants produced more than 6 subcategories, and for the participants with Alzheimer's disease, 13 produced less than 6 subcategories. Therefore, participants with Alzheimer's disease appeared to have a reduced Complexity of Self compared with the control group. For the Measure of Self, the mean Complexity of Self score was 8.4 out of 10 which suggests that the participants had a sense of self made up of a good number of aspects since all the results were close to the maximum.

4.5 Stage 3: Refining the content and administration of the Measure of Self

The following amendments were made:

Refinement of numbers of items

This was to achieve the best balance between ensuring that the measure consisted of enough stimuli to provide useful discrimination but also that there were not so many images that participants became tired or bored. The totals of each 'like me' response were calculated for each image. Any images that produced only 'don't know' responses or were not easily recognised (e.g. the image did not correspond with the 'I am…' statement) were planned to be discarded. However, few of the images met these criteria and as none of the

participants showed signs of tiredness or boredom the ‘Activities’ and ‘Traits and Physical Characteristics’ sets, consisting of 56 and 25 items respectively, were not changed. The method described in section 4.3.3 proved difficult to administer in practice, therefore, a decision was made to reduce the ‘Occupations’ sets by combining types of occupation, e.g. all types of medical professions became ‘health care’, and occupations including secretary, receptionist, office clerk became ‘clerical’. This reduced the number of occupation items from 27 to 19 images for women and 31 to 25 images for men. This meant that the refined test consisted of a total of 100 images for female participants and 106 images for men. This change allowed all the relevant (male or female) occupations stimuli to be shown to each participant, instead of the method described in section 4.3.3 which had proved difficult to administer in practice.

The physical size of the stimuli was also changed after being used with the first 10 participants. Some participants had limited table top space in their homes which meant that it was difficult to position three piles of A4 stimuli in front of the participant. The researcher reduced the size of the stimuli to A5 making them easier to place for the participant, without causing the images to be greatly reduced in size. Using them with the final 10 participants demonstrated that the images were still large enough for the participants to look at without difficulty and even if table top space was limited, the stimuli could be easily viewed and positioned.

Clarification of number of images on each stimulus

All participants were able to successfully select their responses by looking at the single images and/or reading the statements describing the image. The four images on the reverse of the stimuli were looked at by 4 participants, therefore these were considered to be useful and were retained.

Confirm understanding of instructions

The researcher asked review questions during stages 3 and 5 of the Measure of Self. All participants said that they understood the instructions they were given, and the pictures on the stimuli helped them to bring back memories. They also thought the images were representative of the statements.

4.6 Observational behaviours results

Video recordings were made of 19 participants performing the Measure of Self (one participant did not consent to being recorded). The average length of each interview was 29.68 minutes, and a total of 17.76 hours were viewed, with each recording being viewed twice to double check observations had been correctly made and no behaviours had been missed.

Observational analysis of behavioural data

The video recordings were analysed using 'BORIS' version 2.998 (Behavioral Observation Research Interactive Software, downloaded from http://www.boris.unito.it/). This was to enable the use of observations instead of verbal responses to categorise 'Just like me', 'A bit like me' and 'Not at all like me' responses.

A 3-stage process of analysis was used for each participant:

1. First viewing in BORIS; each response was tagged as 'just like me', 'a bit like me' or 'not at all like me', with timings marked.
2. A tally of behaviours was recorded against the categories of behaviour listed in Table 4.6 (section 4.3.3. above) to note behaviours observed for each type of response for each participant.
3. Any additional behaviours not listed in Table 4.6 (e.g. qualifying comment, time spent thinking, holding gaze on image) were added to create a new Video Observation Data Sheet (Table 4.8).

Table 4.8: Video Observation Data Sheet

Type of response	Just like me	A bit like me	Not at all like me	Don't know
Engaged				
Body response related to image				
Brows knitted/lowered/frown				
Conversation/anecdote				
Crying/tearful/wiping eyes				
Eyes crinkled				
Eyes narrowed				
Eyes wide				
Furrowed forehead				
Grimace				
Head leans to one side				
Head moves from side to side				
Head shaking				
Holding gaze on image				
Humming				
Laughing				

Looks at researcher				
Nodding				
Open arm/hand gesture				
Points at image				
Points at self				
Pursed lips down at corners				
Qualifying comment				
Questions researcher				
Raised eyebrows				
Says ‘erm’/hmm/err				
Says ‘phew’				
Seeks approval				
Sighing				
Singing				
Smiling				
Stroking				
Swift, non-hesitant response				
Time spent thinking				
Whistles				
Wrinkled nose				
Looks at all responses				
Says yes/yeh				
Says no/not				
Says just like me				
Says a bit like me				
Says not at all like me				
Makes joke				
Looks at all responses				
Points at response				
Touches face/head				
Refers/reads ‘I am…’				
Emphasis words:				
Neutral				
Passivity				
Staring into space				
Leaving activity area				
Shrugs shoulders				
Sighing				
Asks what is happening				
Physical restlessness				
Mumbling				

The list of behaviours in Table 4.8 was updated as the observations progressed. The recordings of the first 10 participants demonstrated that the list of ‘neutral’ behaviours was unnecessary since all participants were highly engaged, so ‘neutral’ behaviours were removed from the table at this stage.

Also, ‘engaged’ behaviours were removed if they were not observed in any of the first ten participants, resulting in 3 being removed (e.g. humming, eyes crinkled, hand wringing); or scored less than 4 (e.g. eyes narrowed, lips down at corners, shrugs shoulders) The blank rows were used to add any new behaviours that were observed during the first and/or second viewing. These behaviours were: ‘hand touched mouth’, ‘touched ear’, ‘looks down’, ‘looks upwards or into distance’, ‘hand moves side to side’, ‘points at image’.

After the first 10 observations were completed, totals for each ‘like me’ response were calculated. Table 4.9 provides a sample of the results of the first set of 10 observations.

Table 4.9: Observed Behaviours and Responses

Type of response	Just like me	A bit like me	Not at all like me
Brows lowered/knitted	4	15	20
Extended conversation/anecdote	48	34	17
Eyes narrowed	0	0	0
Lips down at corners	0	1	1
Looks at all responses	5	5	10
Movement associated with image	20	10	6
Nodding	114	13	0
Points at self	5	2	0
Shakes head	2	7	148
Shrugs shoulders	0	4	2
Swift non-hesitant response	201	16	183
Wrinkled nose	3	5	11

A new table with a reduced number of responses was created for the remaining 9 participants in order to make the observational scale as efficient and useful as possible.

When all 19 participants’ results were completed, the results were re-examined to establish the coding framework. Initially, behaviours that clearly related to one response only were identified (Table 4.9), i.e. nodding for ‘Just like me’, shaking head for ‘Not at all like me’. Secondly the numbers of participants who had exhibited each behaviour were counted, and behaviours that were exhibited by less than 10 participants were removed from the list. Thus, the first version of the coding framework was created, and included both single behaviours and combinations that indicated a specific response, as shown in Table 4.10.

Table 4.10: Coding Framework Showing Combinations of Behaviours

Just like me	A bit like me	Not at all like me
Single:	**Single:**	**Single:**
Nodding	Looks at researcher	Shakes head
Open hand gesture		Pursed lips
Raised eyebrows		
Holds gaze on image		
Combinations:	**Combinations:**	**Combinations:**
Smile + touches face/head	Frown + touches face/head	Frown +smiles
Smile + movement associated with image	Frown + movement associated with image	Frown + swift response
Swift response + touches face/head	Grimace + touches face/head	Grimace + smiles
Swift response + movement associated with image	Grimace + movement associated with image	Grimace + swift response

4.7 Discussion

The primary aims of this pilot study were to construct a new Measure of Self and then test whether the methods of administration were suitable for use with people with dementia, and find out whether the contents of the Measure (i.e. the stimuli) were appropriate and meaningful for this population.

A further aim of the study was to confirm that the proposed outcome measures could be derived from the data that was collected and to ascertain whether they demonstrated similarities and differences between participants. Each outcome measure is discussed below.

Strength of Self

The pilot study has demonstrated that Strength of Self appears to be a useful outcome measure. There was a reasonable range of results, approximately 27 points between the highest and lowest scores (SD = 7.4), showing that the measure discriminated between participants. There were no floor or ceiling effects so the measure could be used to evaluate interventions because changes in the scoring would be apparent. Also, looking at comments made by participants when they chose their responses suggests that they considered their choices to be accurate. For example, in response to ‘I am lonely’ one participant said:

"Well it's not at all like me. Can I explain to you? It's not in my, not part of my nature to say to be lonely and sit and be sorry for myself. If I think I'm getting lonely I'm out buzzing, and finding my friends, and so on".

In response to 'I am punctual' another participant said:

"Some of the time, a bit like me, I always try to do too many things, that's my trouble".

And in response to 'I am thoughtful', a participant said:

"Well, I always do think about things, whether it actually happens. Like when I go to bed at night, I am always thinking about things, like it's been on my mind about this [interview] *and yesterday I had to go to* {name of hospital} *'cos I had to have an X-ray on my foot and it always comes to my mind the night before so presumably that answers that I am thoughtful. It's just a habit".*

This also confirms the suitability of the statements and accompanying images because participants were able to look at them and quickly understand what aspects of self the statements were referring to. If they were unsure, they asked the researcher for clarifications and were able to act on these.

The high mean score of 82.4% is surprising because Addis and Tippet (2004) reported that strength of identity (comparable with 'strength of self' in this study) was impaired in their participants with Alzheimer's disease, compared with a group of age-matched controls. Addis and Tippet asked their participants to generate their own self-related statements but acknowledged that impairments in the fluency or generative abilities of their participants could affect their abilities to do this. Therefore, this study has demonstrated that providing cues for participants increased their abilities to describe themselves.

Complexity of Self

The results for Complexity of Self demonstrated that it is possible to quantify the multidimensional nature of the self related to the distribution of the 'Just like me' responses across the subcategories of the Measure of Self. All participants demonstrated a preserved self that was multidimensional. These results are comparable with those of Addis and Tippet (2004) who reported that subcomponents of identity were as well preserved in the participants with AD as in the control group.

Quality of Self

Individual participants' proportions of abstract 'Just like me' scores ranged from 22.7% to 50% demonstrating that all participants were able to consider aspects of their selves in more cognitively demanding abstract terms.

Episodic memories

Eighteen participants recalled memories associated with the stimulus they chose as being most important. Just over half of the participants were able to describe general (i.e. semantic) memories, and just over a third produced detailed (i.e. episodic) memories. Thus, this part of the study demonstrated that self-related memories remained intact in a group of people living with dementia and recall of these memories was aided by showing them visual cues. The cues did not have to be specific to the person, e.g. a photograph of him or herself, or a football team that they supported, but by thinking about the cues in relation to themselves, the cues *became* specific to that person.

4.8 Summary

This chapter has provided details of Stages 1 to 3 from Figure 4.1 that have been undertaken in order to develop an effective and meaningful Measure of Self specifically for people living with dementia. Conversations with people living with dementia, before starting to develop the measure, confirmed that a sense of self was still important to them and that they were able to talk about different aspects of themselves. Following this, discussions with expert advisors concerning the usefulness of existing measures of self and identity, ways of investigating self in people with dementia, and aspects of self that could be covered, led to the construction of the new Measure of Self. This measure was based on the conceptual model of self introduced in Chapter 2 and was assembled by taking elements of content and administration from three existing tests, the Twenty Statements Test, the Tennessee Self Concept Scale, and the Self and Identity in Dementia Scale. The new measure was piloted with a group of 20 people living with dementia. The results demonstrated that its content and administration were suitable for this population, and that its outcome measures were meaningful and useful. Interviews with participants were video recorded so that non-verbal responses could be analysed after the interview in order to create a framework of observable gestures and expressions so that the Measure of Self could be used with people who have limited vocabulary.

Chapter 5 reports assessment of the Measure's reliability and validity through testing its implementation with two groups of participants; one group of people living with dementia and one group of people without dementia. Testing the effectiveness of the observational framework will also be reported.

5. Investigating the Psychometric Properties of the Measure of Self

"We went up to the big hospital…. And they were trying to pick out all sorts of things like memory loss…. At that time I found it very unpleasant in the way they put it and the way they were asking. They were trying to prove that I did not have the possibility to have the memory that I knew I had."

('Mrs M', Beard, 2016, pp103-4)

5.1 Introduction

The aim of this project was to develop an objective measure of self that can be used to demonstrate aspects of self that are retained in people living with dementia, using materials and methods that were designed to be sensitive to the abilities of people with impaired cognition. The previous chapter reported Stages 1 to 3 of the 7-Stage process of developing and piloting the Measure of Self, in readiness for testing reliability and validity during Stages 4 to 7. These stages (which are reported in this chapter) are shown in Figure 5.1. This chapter reports the results and findings of Study 2 which investigated the psychometric properties of the Measure of Self, and Study 3 which piloted the observational framework that was created following the pilot study. It will also justify the use of methods and tools that have not been introduced in previous chapters. The version of the Measure of Self used in this study was the version that was refined as a result of the pilot study.

Study 2 had two research aims:

- To psychometrically test the amended Measure of Self by investigating test-retest reliability and convergent validity.
- To confirm whether the Measure of Self could be used with people with moderate to severe dementia and impaired communication abilities.

The aims of Study 2 were achieved by:

- Establishing test-retest reliability by administering the Measure of Self to participants on two occasions, at least two weeks apart.
- Establishing convergent validity by comparing the Measure of Self with two 'gold standard' measures of self and identity.

- Confirming whether the Measure of Self can be used with people with moderate to severe dementia by administering the Measure to participants with more severe cognitive impairments.
- Confirming the effectiveness of the observational framework for people who have impaired verbal capacities as an alternative to them providing verbal responses by administering the Measure to participants with impaired language abilities.

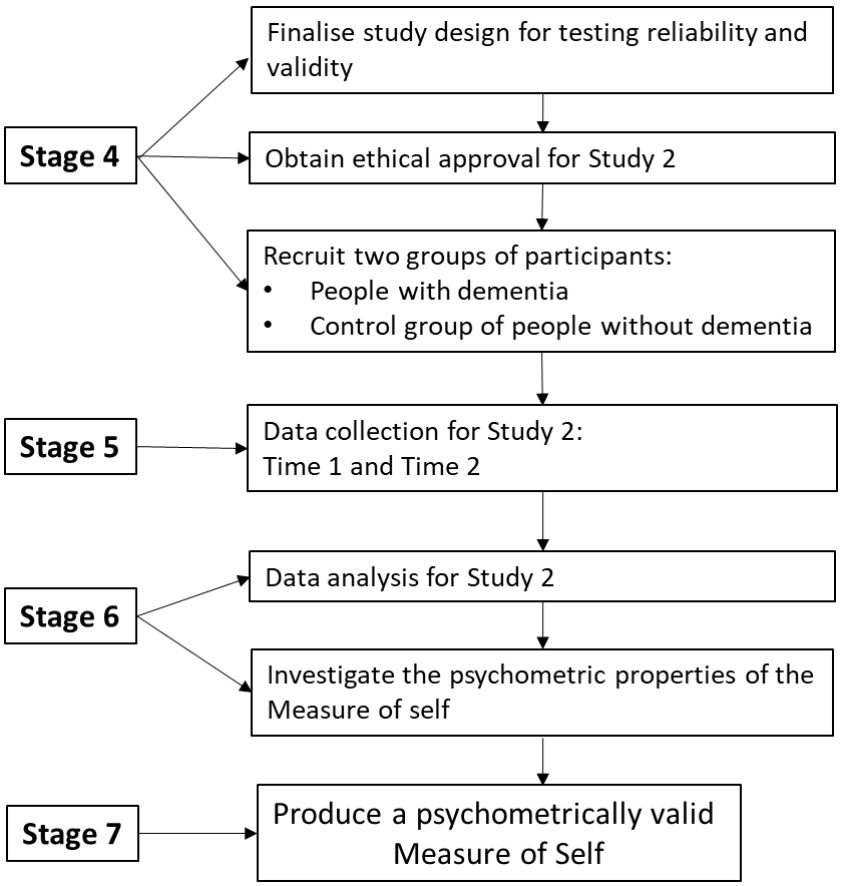


Figure 5.1: Developmental Stages of the Measure of Self

5.2 Stage 4: Finalise Study Design

Figure 5.2 shows the complete set of neuropsychological background tests and experimental measures that were administered to each group, and when they were administered.

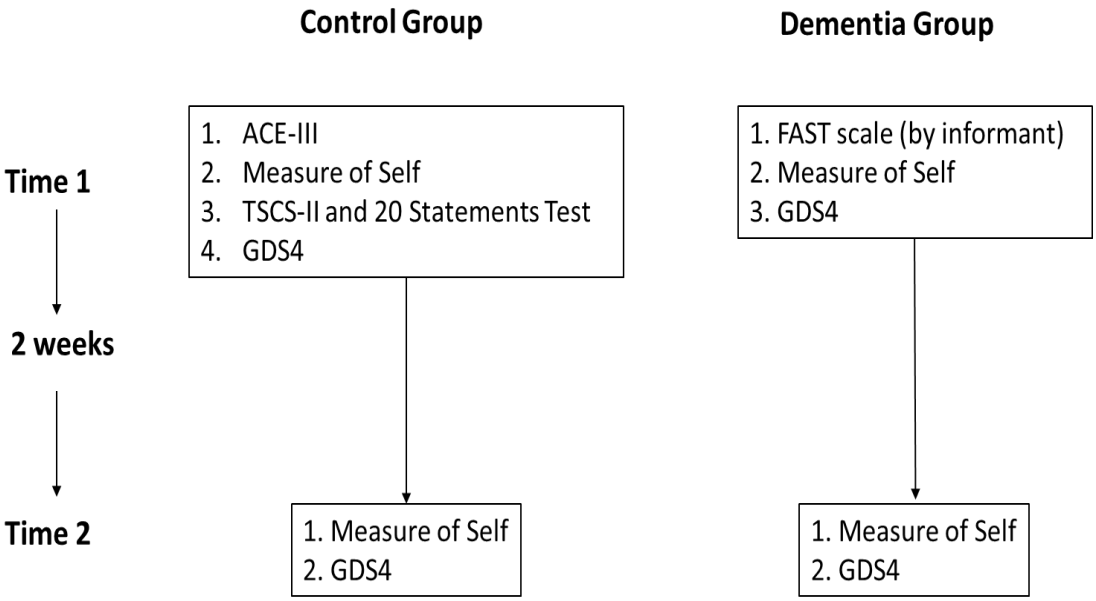


Figure 5.2 Administration of Tests for Test-retest Reliability and Convergent Validity

The following sections will describe the measures, procedures and findings from Study 2.

5.2.1 Ethical approval for Study 2

The study was approved by two ethical committees; the University of Bradford Ethical review panel and the NHS HRA Yorkshire & The Humber – Bradford Leeds Research Ethics Committee reference 17/YH/0176, project ID 212033 (See Appendix XXIII for a copy of the HRA confirmation letter and Appendix XXII for the Study 2 protocol). The ethical application requested approval to recruit people who had been diagnosed with dementia who were able give informed consent, and for those who lacked capacity to consent for themselves. Recruitment of people without dementia who would form the control group was also included in the application.

5.2.3 Participant recruitment and ethical procedures

The researcher contacted managers and organisers of dementia support groups and care homes in Bradford, Leeds, and West Yorkshire, these were different from those contacted for the pilot study so that people with more severe dementia could be approached. The researcher visited support groups where managers had shown interest and gave short presentations to group members, followed by handing out leaflets to any prospective participants who expressed interest. For care home residents, the researcher met with managers

to discuss the project and left leaflets and posters (see Appendix XXIV) that could be displayed, or given to residents by the manager or care staff. Participants for the control group were recruited via the University of Bradford Experts by Experience panel and from a day care centre for service users who were over 60 years of age. One participant for the control group was the wife of a participant in the group of people with dementia. People who were interested contacted the researcher via email or by telephone, or managers asked the researcher to visit again to be given names of people who would like to know more about the study. The researcher then arranged to visit participants at times and places convenient to them. Subsequent interviews took place in participants' own homes, in quiet places in the care home and day centre, or in the participants' rooms or flats.

Before beginning the interviews, the researcher gave prospective participants an information sheet describing the study (see Appendix XXV). As well as details of the study, and what was required of participants, ethical requirements such as confidentiality, right to withdraw and who to ask for further information were stated. The researcher explained that the study required her to visit the participant twice, the second occasion two weeks after the first visit. The researcher advised participants that they could keep the information sheet for a day or so, to show to family or friends if they wished, to help them consider whether or not to take part in the study. However, all participants were happy to continue with the interview during the initial visit (Time 1), and the researcher asked them to sign a consent form. If a participant with dementia was assessed to have capacity to consent but had difficulties reading and/or writing, the researcher read through the consent form with them before assisting them to complete the form. There were two versions of the form; one with text only and one with pictures and fewer words (see Appendix XXV. The researcher asked the participants which they preferred to look at and/or keep, or used her own judgement to decide which version to give them. The researcher also ensured that participants in the control group fully understood the requirements of the study before asking them to sign the consent form.

If the researcher believed that a participant with dementia did not have the capacity to consent a relative or carer who knew the participant well was asked if they thought that the prospective participant would wish to take part in the

study. If the relative or friend agreed to this the researcher asked them to complete a form stating what they thought their relative or friend's wishes would be. If the consultee judged the person would wish to take part, the researcher arranged a day and time for the first interview.

At the end of the interview at Time 1, the researcher asked all the participants if they were happy to be interviewed again after two weeks and if so, a date and time was arranged that was convenient for the participant. The researcher also asked if the participants were happy for her to telephone them on the day of the Time 2 visit to ensure that he or she was still willing to be interviewed.

5.3 Stage 5: Method

Participants

Inclusion criteria for the group of people with dementia were:

- Adults over 65 years with a formal diagnosis of any type of dementia who were residents of care homes or who were attending dementia support groups and/or day centres.
- English-speaking and able to comprehend written and/or spoken words and pictures.
- No significant hearing impairment (with hearing correction if required).
- No significant visual impairment (with correction if required).

The dementia group comprised five people (3 female) who were recruited from a residential home in North Leeds (n = 4), and a dementia support group, also in Leeds (n = 1). Their age range was 76 to 92 years (mean = 85.2, SD = 6.4); age at leaving school ranged from 15 to 18 years. Two participants had attended evening classes after leaving school and one had completed a university degree course. Severity of dementia was assessed by the FAST Scale of functional abilities (Reisberg, 1988, scoring range from 1 = normal to 7 = severe dementia) by asking someone who knew the person well (a member of staff in the residential home for four participants, and the wife of a participant who lived in his own home for one participant). It was planned to assess the cognitive abilities of members of the dementia group with either the ACE-III or the FAST scale. However, the carers indicated that the participants were all at a moderate to severe stage of dementia, with scores ranging from 6c to 6e with reference to the FAST scale. This indicated that the participants were

experiencing memory loss and anxiety, therefore the researcher considered that asking them to complete the ACE-III was likely to cause anxiety because of memory related questions at the start, so only the FAST scale was used. Diagnoses for three of the participants were Alzheimer's disease, vascular dementia and mixed dementia. For the remaining two participants the type of dementia was unknown. Four of the participants were able to give informed consent, and consent for the remaining participant was provided by his wife. Two participants had impaired speech, predominantly word finding difficulties. Inclusion criteria for the control group were:

- Adults aged over 65 years of age with no objective memory impairment.
- English-speaking and able to comprehend written and/or spoken words and pictures.
- No significant hearing impairment (with hearing correction if required).
- No significant visual impairment (with correction if required).

The control group comprised 6 people (5 female) who were recruited from service users' groups in West Yorkshire. Their age range was 65 to 84 years (mean = 72.5, SD = 7.1); age at leaving school ranged from 16 to 18 years. Three participants had completed college courses and one had completed a university degree course. All participants gave informed consent, and completed the Addenbrooke's Cognitive Examination III (ACE-III, Hseih et al, 2013) before starting the measures. The ACE-III was used as a screening tool with a score of 82 out of 100 indicating cognitive impairment (Noone, 2015), so scores at or below this cut-off point would have excluded participants from the control group. However, the scores ranged from 84 to 99 (Mean = 92.8, SD= 5.8) so no participants were excluded.

All participants from both groups were also asked to complete the 4-item Global Depression Scale (GDS4, Shah et l, 1997) at the end of the testing sessions; a score of 2 to 4 indicates possible depression. None of the participants with dementia or the control participants reported serious depression. The scores ranged from 0 to 1, so it was not possible to investigate the effect of depression on sense of self or conclude that depression was or was not an influence on the scores.

5.4 Materials and Procedures

The materials for the refined Measure of Self consisted of 100 stimuli for female participants and 106 stimuli for male participants. The number was larger for male participants because they were shown more occupations in the Relationships and Occupations set of stimuli. Each stimulus consisted of an "I am…" statement with one image to illustrate the statement printed on the front of an A5 laminated card. The reverse of the card displayed the printed statement with 4 different images illustrating the statement (see Chapter 4, section 4.2.4 for an example).

The Measure of Self consisted of three phases (see section 5.3). For the first and second phases the researcher read standardised instructions that matched each set of stimuli (i.e. i) Activities, ii) Traits and Physical Characteristics, and iii) Relationships and Occupations). The instructions for the third phase of the measure, were also read out (see Appendix XX for examples of sheets). This ensured that all participants received the same instructions. An observational check list, as described in Chapter 4, section 4.6 was used with participants who had difficulty communicating verbally in order to assess their responses during the matching and sorting phases of the interview. This consisted of the list of facial expressions or gestures which had been established during the pilot study (see also section 4.6).

5.4.1 Outcome measures

Strength of Self was measured by combining the total numbers of 'Just like me' and 'Not at all like me' responses. The maximum score for strength of self was 100 for female participants and 106 for males, because these were the maximum numbers of stimuli shown. All scores were converted to percentages to make the males comparable to the females.

Complexity of Self was defined as the numbers of categories and subcategories of the Measure of Self chosen as 'Just like me'. Categories were Activities, Traits and Physical Characteristics, and Relationships and Occupations (three in total). Subcategories were: Hobbies, Sports, Outdoor, Indoor, Social, Abstract, Traits, Physical, Relationships, Occupations (10 in total).

Quality of Self was related to the concrete and abstract nature of the stimuli which comprised 67 concrete statements for female participants and 73 for men (because of the greater number of occupations), with 33 abstract statements for both genders (see also section 4.2.3). Quality of self was quantified by calculating the respective percentages of abstract and concrete statements chosen as 'Just Like Me' from the total selected by each participant. However, for the reliability and validity assessments in this study only the scores for the abstract statements were used as outcomes to judge quality of self, following Addis and Tippet's (2004) description of abstract concepts equating to quality of identity.

Events that a participant remembered relating to the stimulus chosen as being most important were scored according to the Episodicity Rating Scale used in the Autobiographical Memory Interview (AMI, Kopelman et al, 1998). Each memory relating to the most important stimulus was given a score ranging from 0 to 3 with higher scores indicating detailed episodic memories, specific in time and place

5.5 Assessing psychometric properties

The Measure of Self was assessed for psychometric validity by investigating test-retest reliability and convergent validity. For test-retest reliability the Measure of Self was carried out by all participants on two separate occasions, two weeks apart (see figure 5.2). This time scale was based on a study investigating awareness in people with dementia by Parrao et al (2016) who developed a structured interview to assess insight and judgement in dementia. The aim was to include an interval that would provide a reasonable time between successive administrations but not so long that there would have been progression of cognitive impairment.

For convergent validity the Measure of Self was compared with two 'gold standard' measures that investigate self-concept and identity: the Twenty Statements Test (TST, Kuhn & McPartland, 1954) and the Tennessee Self Concept Scale II (TSCS-II, Fitts and Warren, 1996). These measures were considered to be the closest match to the Measure of Self for convergent validity, as there are no comparable tests of self for people with dementia or other types of cognitive impairment. The TST is suitable for use by people of all ages, and was validated by McCrae & Costa (1988) with participants ranging

from 32 to 84 years of age, so covers the age range of control participants in this study (65 to 84 years). The TSCS-II measures three components of self-concept (behaviour, satisfaction and identity) over 5 domains (physical, personal, family, moral and social). It consists of a questionnaire consisting of 82 descriptive statements (for example “I am an honest person”) that are rated for self-descriptiveness on a 5-point Lickert true/false scale (5 = ‘always true’ to 1 = ‘always false’). It has been shown to be suitable for people aged between 13 and 90 years, therefore is suitable for the age range of participants in this study. However, in recognition of the fact that the gold standard measures have not been validated or adapted for people with dementia only the control group were asked to complete the gold standard measures at Time 1, as shown in Figure 5.2.

5.5.1 Administration of the Measure of Self

The administration of the Measure of Self consisted of 3 phases:

- ***Practice phase*** to ensure that participants understood the instructions and were able to choose responses after looking at ‘I am…’ stimuli.
- ***Matching phase*** when participants matched the ‘I am…’ stimuli to the response cards.
- ***Sorting and memories phase*** in which participants chose the stimulus that was most important to them and were asked to talk about a memory or memories related to the stimulus.

The three phases were each administered following the same procedures as the pilot study (section 4.3.3) for all participants, at Time 1 and Time 2, but without the review questions and no video recordings were made. All participants were able to go at their own pace and the researcher asked at the end of each phase if they were happy to continue, or would like a break. Everyone was happy to continue the sessions without a break. The Measure of Self took approximately 30 to 40 minutes to complete.

5.5.2 Administration of the Gold Standard Measures

The procedures for the TST and TSCS-II were the same as those used by Addis and Tippet (2004) who administered these tests to a group of 20 people without dementia, age range 65 to 88 years. In the standard version of the TST participants are asked to write down 20 “I am…” statements in the order that they come to mind, without worrying about importance or logic. For example, “I

am a cricket enthusiast; I am a father". Typically, there is no time constraint as participants are asked to stop when they have generated 20 statements. For ease of use with older adults Addis and Tippet asked participants to give their statements verbally and a researcher wrote the statements down on answer sheets. For the TSCS-II, Addis and Tippet only used the 'Identity' component, consisting of 21 statements drawn from the complete set of 82 statements. Again instructions were read aloud by the researcher with the 21 statements presented individually. The 5-point true to false scale was also printed on each card. Copies of the TST and identity component of the TSCS-II can be found in Appendix XXVII and Appendix XXIX.

Presentations of the TST and TSCS II were counterbalanced before and after the Measure of Self (MoS), as shown in Table 5.1, to exclude order effects (P1 to P6 represent participants). Each of the gold standard tests took up to 5 minutes to complete.

Table 5.1

Order of Presentation of Measures to Participants

P1: TST → TSCS → MoS

P2: MoS → TSCS→ TST

P3: TSCS → TST → MoS

P4: MoS → TST → TSCS

P5: TST → TSCS → MoS

P6: MoS → TSCS →TST

5.6 Stage 6: Results

The first set of results will focus on the test-retest reliability of the Measure of Self. Statistical analysis was performed using IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp.

Test-retest reliability

Test-retest reliability was assessed for each outcome measure resulting from the Measure of Self at Time 1 and Time 2 for both groups as follows:

Strength of self

Strength of self scores for the dementia group at Time 1 ranged from 82% to 97% (mean = 90.2%, SD = 6.1) and at Time 2 from 86% to 95% (mean = 91.6%, SD = 3.6). Scores for the control group ranged from 75% to 94% at

Time 1 (mean = 86.5%, SD = 8.1) and from 79% to 93% at Time 2 (mean = 80.6%, SD = 9.8). Test-retest reliability was assessed using a two way repeated measures ANOVA to investigate if there were any differences between the strength of self scores of each group after the two-week time period. There was a main effect of group which was close to significance ($F(1.9) = 4.23$, $p = .07$, $ηp^2 = .32$), showing that the dementia group demonstrated a slightly stronger sense of self (mean = 90.9%) than the control group (mean = 83.6%) over both time periods. Figure 5.3 illustrates the mean scores of both groups at Time 1 and Time 2. In contrast, there was no significant main effect of Time ($F(1,9) = .63$, $p = .45$, $ηp^2 = .07$) and no significant interaction between Time and Group ($F(1,9) = 1.68$, $p = .23$, $ηp^2 = .16$), showing similar performances of both groups at Time 1 and Time 2, and confirming acceptable test-retest reliability of the Measure of Self in terms of Strength of Self.

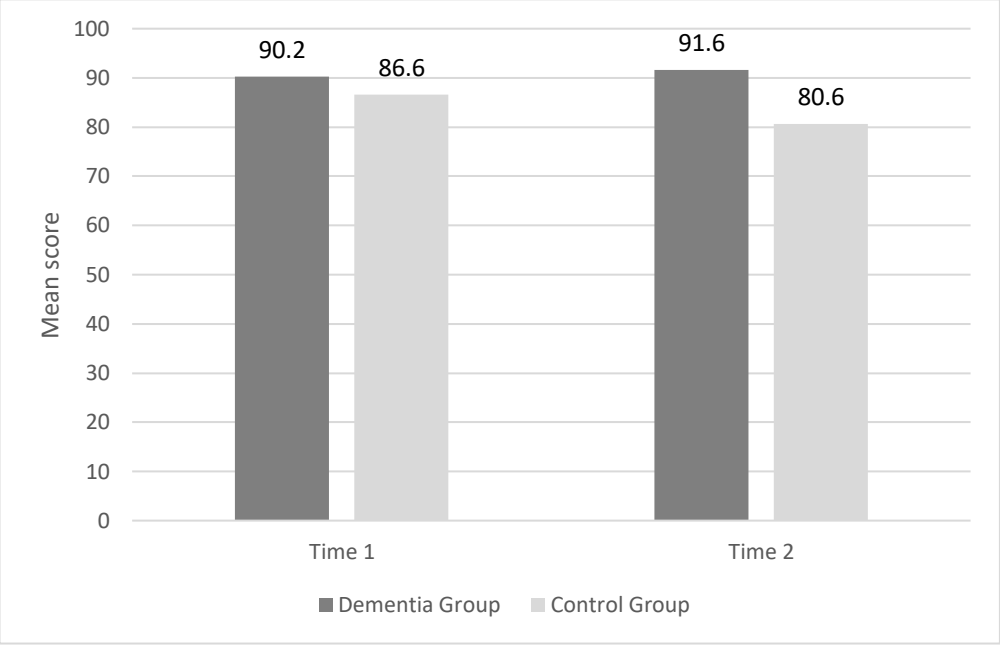


Figure 5.3 Mean Strength of Self scores

Complexity of Self

The results for the numbers of categories were the maximum of 3 for both groups at both time periods therefore no comparison tests were performed. For numbers of subcategories, the dementia group score ranged from 9 to 10 (mean = 9.6, SD = .55) at Time 1, and at Time 2 from 8 to 10 (mean = 9.4, SD = .89). The numbers for the control group ranged from 8 to 10 (mean = 9.33, SD = .82) at Time 1, and from 7 to 10 (mean = 8.83, SD = .98) at Time 2. These

results demonstrate that the majority of participants in both groups selected aspects of their selves from nearly all the categories. Furthermore, these numbers show that the dementia group were slightly more consistent than the control group across Time 1 and Time 2, and showed slightly more complex self descriptions by choosing stimuli from more categories. A 2x2 repeated measures ANOVA showed no main effect of Time ($F(1,9) = 1.17$, $p = .31$, $\eta p^2 = .12$), or significant interaction between Group and Time ($F(1,9) = .21$, $p = .65$, $\eta p^2 = .02$). There was no significant difference between the groups ($F(1,9) = 1.15$, $p = .31$, $\eta p^2 = .11$). This demonstrates acceptable test-retest reliability of the Measure of Self in terms of complexity of self which was similar for both groups at Time 1 and Time 2.

Quality of Self

For the dementia group at Time 1, the range of abstract scores was 30.56% to 50% (mean = 39.61%, SD = 8.6), and at Time 2 the range was 35.71% to 48.72% (mean = 42.33%, SD = 5.6). For the control group, the range at Time 1 was 30% to 48.48% (mean = 41.85%, SD = 6.2) and at Time 2, 35.41% to 50% (mean = 43.98%, SD = 4.9). A two-way repeated measures ANOVA was conducted to explore the differences between the Quality of Self scores of the dementia and control groups at Time 1 and Time 2. There was no main effect of time ($F(1,9) = 1.25$, $p = .29$, $\eta p^2 = .12$) and no significant interaction between time and group ($F(1,9) = .018$, $p = .89$, $\eta p^2 = .002$). There was no significant difference between the groups ($F(1,9) = .37$, $p = .56$, $\eta p^2 = .04$). These results confirm test-retest reliability for both groups for Quality of Self because the scores at Time 1 and Time 2 were stable.

Figure 5.4 illustrates the similarities between the mean Quality of Self scores at Time 1 and Time 2, for both groups, with approximately 40% of responses being abstract, and both groups increased slightly at Time 2.

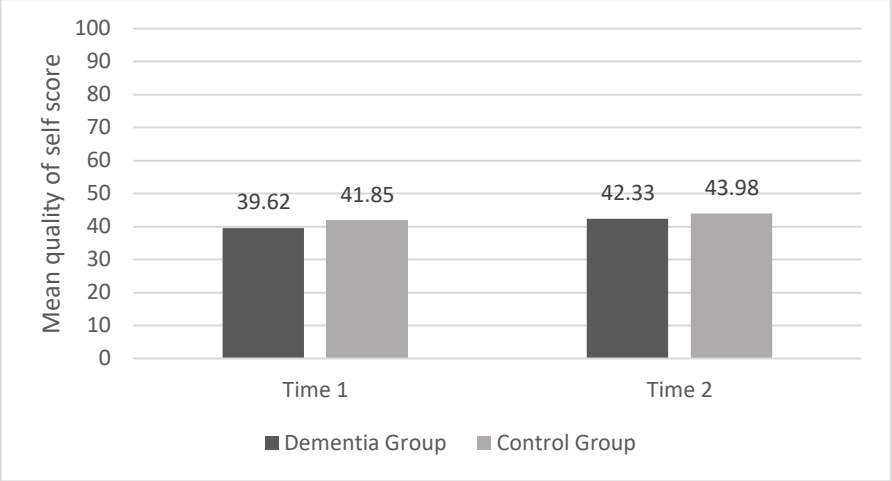


Figure 5.4 Mean Quality of Self Scores at Time 1 and Time 2

Episodicity Scores

Participants in the control group gave 10 accounts (one participant was unable to think of any specific memories on either occasion). Participants in the dementia group gave 9 accounts; one participant was unable to give an account at Time 1 because she had lost her hearing aid so the researcher was unable to explain clearly what the participant should do. However, her hearing aid was found at Time 2 and the participant was able to recall a memory. Table 5.2 lists the stimuli chosen as most important by both groups at each time period.

Table 5.2 Stimuli Chosen as Most Important

Participant ID	Time 1	Time 2
Dementia Group		
DG201	Good manners	Helpful
DG202	Honest	Care worker
DG203	(Missing)	Punctual
DG204	Engineer	Husband
DG205	Grandmother	Happy
Control Group		
CG201	Mother	Mother
CG202	Wife	Lonely
CG203	Religious	Religious
CG204	Religious	Religious
CG205	Husband	Husband
CG206	Family person	Family person

There was a clear difference between the groups; for the participants with dementia, the most important stimuli were different at Time 1 and Time 2, whereas for all but one member of the control group, the most important stimuli were the same (participant CG202 who changed from ‘wife’ at Time 1 to ‘lonely’

at Time 2 talked about being lonely after her husband had died), and the memories recalled by members of the control group were very similar on both occasions.

Unlike the pilot study, the researcher did not use video recordings so was not able to transcribe memories. Instead she made notes of what participants said, emphasising details that were episodic in nature, which is the method normally used when administering the Autobiographical Memory Interview. Episodicity scores ranged from 0 to 3 for both groups. For example, one participant in the dementia group, scoring 3, talked at length about being an engineer in the Royal Navy during World War II (responding to 'I was an engineer'), He described how he serviced aircraft on board aircraft carriers, and he said that it was very dangerous on the flight deck because pilots did not look out for individuals. Another participant with dementia scored 0 at Time 1 when she remembered being honest by putting money in an honesty box, which was the image on the stimulus ('I am honest'). However, at Time 2 her score was 2 because she was able to talk about being a care worker in a hospital for women in Sheffield ('I was a care worker'), how she enjoyed seeing babies and helping new mums settle in. One participant in the control group who chose 'I am a mother' as her most important stimulus scored 3 on both occasions by relating two different memories. The first was when she heard about the birth of her first grandchild. She and her husband were staying in the Palace Hotel in San Francisco and she described the joy that they both felt. The second memory was of the pride she felt when she saw her son in a play at school ('Oh What a Lovely War'), but it was also very emotional because the performance was on the same day as her mother died, so she had not wanted to go to the play. A second participant in the control group scored 1 at Time 1 because she could remember places she had visited with her husband but no specific occasions (responding to 'I am a wife'), and 0 at Time 2 because she felt lonely (responding to 'I am lonely') without her husband.

Comparing the episodicity ratings, there were differences between the mean scores. For the dementia group, at Time 1, mean score was 1.4 (SD = 1.5) and 1.6 (SD = 1.1) at Time 2. For the control group, at Time 1 the mean score was 2.3 (SD = 1.2) and 2.0 (SD = 1.6) at Time 2. A two-way repeated measures ANOVA demonstrated that there was no main effect of time ($F(1,9) = 0.27$, $p =$

.873, ηp^2 = .003), no interaction between group and time (F (1,9) = .388, p = .433, ηp^2 = 0.46) and no difference between the groups (F (1,9) = .85, p = .381, ηp^2 = .086). These results again show good test-retest reliability.

Figure 5.5 illustrates that scores slightly increased for the dementia group, and decreased for the control group. The lower scores for the dementia group may be due to them mostly choosing traits as their most important stimuli, so it would be difficult to remember specific instances of being honest or punctual, for example. Their comments tended to be about having been 'brought up' to be that way and always having been so, whereas participants in the control group were able to describe specific family events.

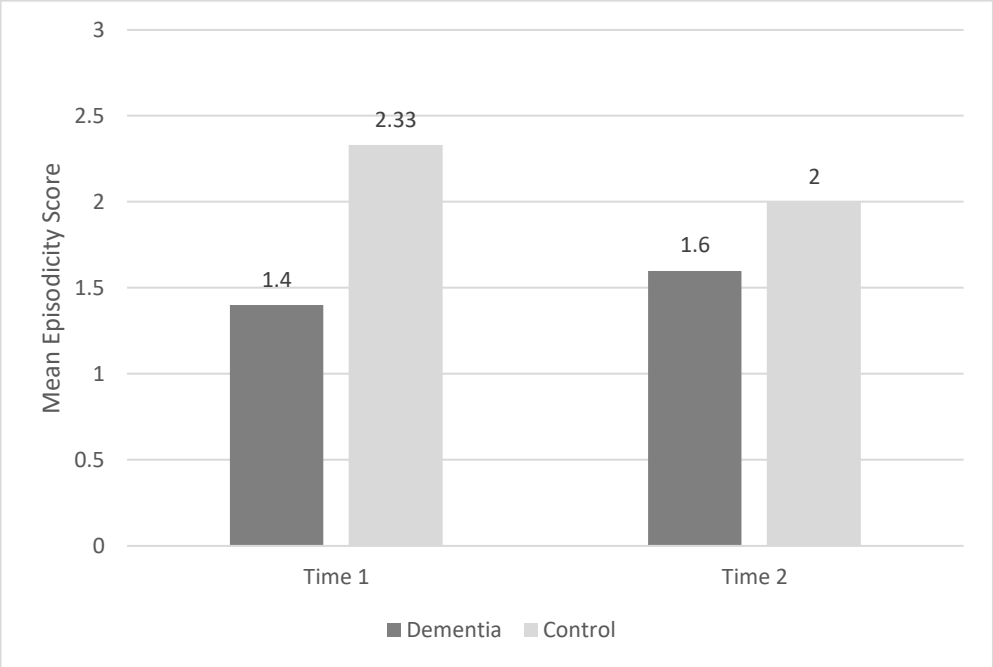


Figure 5.5 Mean Episodicity Scores

Convergent Validity

Convergent validity was tested by comparing the results of the control group's Measure of Self at Time 1 with the TST and TSCS scores. The methods of scoring the TST and TSCS were the same as those used by Addis and Tippet (2004). Table 5.3 summarises the outcome measures for each of the tests.

Table 5.3: Outcome Measures and Methods of Calculation

Outcome measure	Twenty Statements Test	Tennessee Self Concept Scale-II	Measure of Self
Strength of Self	The total number of valid statements, e.g. 'I am honest', 'I am good at giving advice'. Non-valid statements describe activities rather than qualities, e.g. 'I am going to the hairdressers', 'I enjoyed going on a cruise'.	Total number of 'definite' responses, i.e. 'always true' and 'always false'	Total number of 'Just like me' and 'Not at all like me' responses.
Complexity of Self	Numbers of categories and subcategories	Not applicable	Numbers of categories and subcategories chosen as 'Just like me'.
Quality of Self, divided into abstract and concrete statements	Percentage of responses coded as abstract	Not applicable	Abstract statements calculated as percentage of 'Just Like Me' responses.

Strength of Self

The TST and TSCS-II total scores were compared with the Measure of Self Strength of Self scores. The maximum score for the TST is 20, and for the Measure of Self it is 100 for women, and 106 for men (converted to percentages). The TST scores ranged from 9 to 20 (mean = 15.17, SD = 4.02) and the Measure of Self scores ranged from 75 to 94 (mean = 86.5, SD = 8.07). A Pearson Correlation showed a strong relationship (n = 6, r= -.842, p = .036) between the two scores. The maximum Strength of Self score for the TSCS-II is 105. The scores for the TSCS-II ranged from 18 to 55 (mean = 32.17, SD = 15.37). Comparing these scores with the Measure of Self, a Pearson Correlation showed a weak relationship between the two scores (n = 6, r = -.334, p = .518). These results demonstrate a good convergent relationship between the TST and Measure of Self in terms of Strength of Self, but a poor convergence between the TSCS-II and Measure of Self.

Complexity of Self

Complexity of self was calculated by counting the numbers of categories and subcategories generated in the TST, and categories and subcategories chosen as 'Just like me' for the Measure of Self. For the TST, categories were: Attributes, Social identities, Evaluative descriptions and Physical (maximum number was 4). Subcategories were: Activities, Psychological Traits, Social Descriptions (that were not specifically identities), Autonomous, Family, and Aspirations (maximum number was 6). These were based on categories and subcategories specified by Addis and Tippet (2004) and Rhee et al (1995). For the Measure of Self, categories and subcategories were the same as those listed in section 5.4, with maximum scores of 3 and 10 respectively.

Scores for categories in both measures were very similar (range 3 to 4 for the TST, and all scores were 3 for the Measure of Self) so could not be compared using Pearson Correlation. Subcategory scores ranged from 4 to 6 (mean = 5.33, SD = .82) for the TST, and from 8 to 10 (mean = 9.33, SD = .82) for the Measure of Self. A Pearson Correlation showed a weak relationship between the two sets of scores (n = 6, r = .20. p = .704), therefore convergent validity between the TST and the Measure of Self is poor.

Quality of Self

Quality of Self scores for the TST and the Measure of Self, represented by the proportions of abstract statements, were compared using Pearson Correlation. The TST scores ranged from 26.67% to 93.33% (mean = 51.67%, SD = 27.1); the Measure of Self scores ranged from 30% to 48.48% (mean = 41.85%, SD = 6.2). There was a moderately large correlation between the two sets of scores (n = 6, r = -.691, p = .128) suggesting that there is reasonably good convergent validity between the TST and Measure of Self in terms of Quality of Self. However, this result should be considered with caution as the range of scores for the TST was very wide and a larger group of participants may provide more valid results.

ACE-III scores

Although not directly relevant to assessment of convergent validity, the ACE-III scores (range 84 to 99, mean = 92.8, SD= 5.8), completed by the control group only, were compared with TST total scores and quality of self scores, TSCS definite scores, and Measure of Self Strength of Self and Quality of Self at Time 1. There were significant correlations between the ACE-III and TST total score

(n = 6, r = .943, p = .005), and with the Measure of Self Strength of Self (n = 6, r = .847, p = .033). No other correlations were significant.

5.7 Study 3: Piloting the Observational framework

None of the participants recruited for Study 2 had communication difficulties that were so severe that the observational checklist needed to be used. Therefore, three more participants were recruited who had difficulty speaking in order to test the framework. It was intended that all three should complete the Measure of Self on two occasions, as far as possible repeating the same procedures as Study 2. However, one participant with the most severe dementia became ill in the week following Time 1 so the researcher was unable to complete Time 2 procedures.

5.7.1 Method

Participants

Three participants (all female) with severe memory loss and limited vocabulary were recruited by the researcher from an extra care residential home in Bradford. They all lived in single apartments and the researcher was introduced to the participants by care workers who knew them well. The participants ages ranged from 75 to 84 years. Their names were ‘Daphne’, ‘Pamela’ and ‘Evelyn’ (names changed for anonymity). Two of the participants had been diagnosed with Alzheimer’s disease and/or dementia. Daphne had difficulty understanding what was said to her and was unable to form complete sentences. Evelyn had severe memory loss and was reluctant to speak because she could not follow conversations and complete sentences herself. Pamela had no formal diagnosis of dementia; she had severe expressive difficulties but was able to understand other’s speech. The carer of one participant was consulted about consenting to take part; two participants were judged to be able to consent themselves. The researcher did not ask any of the three participants to complete the ACE-III because their verbal difficulties would have prevented them from responding to it. Therefore, FAST scores were used to indicate their level of impairment; these scores were 6c for two participants and 7a for the remaining participant, indicating severe and very severe cognitive impairment. Because of the small number of participants their results will be reported individually, and compared with group scores from the previous studies, to indicate similarities and differences.

Procedure

The Measure of Self was administered using the same materials and following the same procedures as described in section 5.5.1, using the observational checklist to confirm their desired responses of how well they thought the stimuli described them. However, the researcher was unable to administer all of the phases of the Measure to the three participants. Daphne became fatigued after looking at two sets of stimuli during Time 1, and the researcher was unable to follow up with a Time 2 visit. However, her results will be reported because she responded well to the stimuli that were presented to her. Evelyn and Pamela were also only able to complete two sets of stimuli because they became fatigued after sitting up to a table for approximately 30 minutes, and neither completed the Matching and Memories phase of the measure. The researcher was able to visit them on a second occasion and collect sufficient data to be able to compare their Strength, Complexity and Quality of Self scores over Time 1 and Time 2.

5.7.2 Results

Strength of Self

Daphne responded to 32 'Activities' stimuli and 14 'Traits and Physical Characteristics' stimuli; her Strength of Self score was 88.9%. Evelyn and Pamela completed full sets of 'Activities' and Traits and Physical Characteristics' on both visits. Evelyn's Strength of Self scores were 73.7% at Time 1, and 67.1% at Time 2, Pamela's were 96.1% at Time 1 and 92.1% at Time 2.

Complexity of Self

All three participants responded by choosing stimuli from each of the 8 subsets presented to them so all had Complexity of Self scores of 8 at Time 1, and the same for Pamela and Evelyn at Time 2.

Quality of Self

Daphne's Quality of Self score was 42.3%, Evelyn's was 48% at Time 1 and 47.8% at Time 2, and Pamela's scores were 27.1% and 28.9% respectively.

Table 5.4 illustrates how Daphne, Evelyn and Pamela's scores compare with the group results from the Pilot study and Study 2.

Table 5.4 Comparison of Outcome Measures for All Groups of Participants

	Strength of Self		Quality of Self		Complexity of Self	
Participants	**Time 1**	**Time 2**	**Time 1**	**Time 2**	**Time 1**	**Time 2**
Daphne	88.9%		42.3%		8/8	
Evelyn	73.7%	67.1%	48%	47.8%	8/8	8/8
Pamela	96.1%	92.1%	27.1%	28.9%	8/8	8/8
Pilot study group*	82.4%		38.3%		8.4/10	
Study 2 dementia group*	90.2%	91.6%	39.6%	42.3%	9.6/10	9.4/10
Study 3 control group*	86.5%	80.6%	41.8%	43.4%	9.3/10	8.8/10

* mean scores

The results show that Daphne's scores were comparable with the groups from the pilot study and Study 2; Evelyn's Strength of Self scores were lower than the mean scores for all the groups, but her Quality of Self scores were comparable. Conversely, Pamela's Strength of Self scores were slightly higher than the mean scores, but her Quality of Self scores were lower. It is not possible to conclude that the Complexity of Self scores were all comparable but it appears that Daphne, Pamela and Evelyn all expressed multiple aspects of themselves at a level similar to the other groups.

This demonstrates that the Measure of Self was effective when used with participants with limited speech because it indicated that they could perform elements of the measure in spite of their impairments, and that the results were consistent across Time 1 and Time 2. This also demonstrates that the stimuli that were presented to the participants were appropriate for them in terms of their format and content.

Observational Checklist results

The researcher wrote the participants' responses on their answer sheets, with notes of facial expressions and gestures whilst presenting the stimuli, with reference to the Observed Behaviours Checklist (Table 5.5)

Table 5.5 Observed Behaviours Checklist

Just like me	A bit like me	Not at all like me
Single: Nodding Open hand gesture. Raised eyebrows. Holds gaze on image. **Combinations:** Smile + touches face or head. Smile + movement associated with image. Fast response + touches face or head. Fast response + movement associated with image.	**Single:** Looks at researcher. **Combinations:** Frown + touches face or head. Frown + movement associated with image. Grimace + touches face or head. Grimace + movement associated with image.	**Single:** Shakes head. Pursed lips. **Combinations:** Frown + smiles. Fast response + frown Grimace + smiles. Fast response + grimace

Table 5.6 below indicates how many times each participant performed the listed behaviours, but it is important to note that in most instances the participant said 'yes' or 'no' in addition to showing a facial expression or bodily movement, or responded quickly and only said 'yes' or 'no', indicating 'Just like me' or 'Not at all like me'.

Table 5.6 Gestures and Expressions Noted for Each Participant

Gesture/expression	Daphne Time 1 only	Evelyn Times 1+2	Pamela Times 1+2
Just like me: single			
Nodding	7	6	13
Open hand gesture			1
Raised eyebrows	3	1	1
Holds gaze on image			
Laughs[2,3]		1	1
Sad/regretful expression[3]			9
Eyes wide[1,3]	1		5
Just like me: combinations			
Smile + touches face or head			
Smile + movement associated with image			
Fast response + touches face or head			
Fast response + movement associated with image		2	7
Eyes widen + smile[3]			2
A bit like me: single			
Looks at researcher			
Wrinkled nose[1,2]	1	1	
Movement associated with image[2]		2	
Grimace[1]	1		

A bit like me: combinations Frown + touches face or head Frown + movement associated with image Grimace + touches face or head Grimace + movement associated with image			
Not at all like me: single Shakes head Pursed lips Wrinkled nose[1,2,3] Laughs[2,3] Frown[1]	3 2 1	6 4 1	8 4
Not at all like me: combinations Frown + smiles Fast response + frown Grimace + smiles Fast response + grimace			1 1

Behaviours marked with [1,2,3] were idiosyncratic gestures or expressions used by Daphne, Evelyn and Pamela respectively. Pamela, who had the most severe speech impairment, showed more facial expressions than Daphne or Evelyn. For example, her eyes lit up and she looked happy when one of the stimuli showed something that was particularly important to her, and her expression changed from neutral to sad or regretful if the stimulus was something she enjoyed in the past but is no longer able to do because of her physical and visual problems.

In addition, all three participants were able to make short verbal utterances, hence there were fewer gestures and expressions observed than the researcher had expected. All the participants made comments about many of the stimuli, and briefly described semantic and episodic memories related to the stimuli. Thus, participants who usually found it difficult to make themselves understood in conversation, were able to describe a trait or activity very clearly. For example, in response to 'I was a redhead' Daphne replied quickly and commented about having fair skin, demonstrating that she was able to think about something related to the stimulus, not just the stimulus itself. She also made comments about activities, such as *"no chance"* to 'I was a driver', and *"perfect"* to 'I am a knitter'. These were all indications that Daphne was thinking about, and responding to the stimuli.

Pamela was also able to describe many aspects of her past life. For example, in response to 'I am a fisherman' she replied *"Yes, with Dad. That's a good one*", and responding to 'I am a gardener' she said *"We had to get what we could".* She talked about being active at school: *"Mine were like running, swimming, yes"*, and with regard to 'I am a football fan' she said *"Yes, I like that very much, that's the first one"* meaning she liked that sport the best.

It was clear that Evelyn liked listening to *"most kinds of music, not heavy or opera"*, and had enjoyed caravanning and walking in the Yorkshire Dales. At first she could not remember where their caravan was sited, then when responding to 'I am a walker' she said straight away, *"We had a caravan in Knaresborough".* When responding to 'I was blonde' at Time 1 she said that at school she was *"absolutely white"*, and at Time 2 she said *"drip white"*. She also described how the school nit nurse had told her that because of her hair *"If you stood over there they'd [nits] find you over there".*

5.8 Discussion

The aims of the studies reported in this chapter were to investigate the psychometric properties of the new Measure of Self in terms of test-retest reliability and convergent validity, and pilot the observational checklist.

5.8.1 Test -retest reliability

Overall, test-retest reliability was shown to be good for all the outcome measures that were specified for the Measure of Self. Starting with Strength of Self, there were no significant differences between the scores at Time 1 and Time 2 for the group of people with dementia and the control group. However, an interesting finding was that the participants with dementia had slightly higher Strength of Self scores than those without dementia. Addis and Tippet (2004) assessed the strength of identity of people with mild Alzheimer's disease using the TST, comparing the results with a group of people without dementia. They reported that the group with Alzheimer's disease generated fewer statements than the control group, suggesting a weakened sense of self. But they also suggested that Alzheimer's disease may affect a person's fluency and ability to generate statements so the smaller number of statements may be caused by an inability to generate 'I am…' statements, rather than an actual loss of self. The results from the Measure of Self suggest that giving people cues in the form of written statements and images help to bring aspects of self and identity to mind,

and provide simple ways of helping them to describe or indicate these aspects. This method can be said to be reliable because the Strength of Self scores remained the same after the two-week interval.

For Complexity of Self, there were again no significant differences between scores at Time 1 and Time 2, and the participants with dementia scored slightly higher than the control group. This is a similar result to what was reported by Addis and Tippet (2004) who found no significant difference between the numbers of categories and subcategories produced by participants with Alzheimer's disease and their control group. However, Addis and Tippet (2004) commented on their results by questioning the validity of the similarity between the results for their Alzheimer's disease and control groups because the researchers added prompts to the instructions given to both groups (e.g. suggesting that the participants think about characteristics, roles, and abilities). Addis and Tippet speculated that these prompts may have primed the participants with Alzheimer's disease to generate similar self-descriptions to the control group, thus hiding a difference in ability to generate self-descriptions between the two groups. It can be argued that the cues provided by the Measure of Self stimuli provided a similar set of prompts. However, participants in this study were able to think about each stimulus and grade how well they thought the statements described them. In many cases, they made comments reinforcing the response they gave, such as having been brought up to be honest and hard-working, or being able to swim when they were younger, but no longer doing this. Therefore, it can also be argued that the stimuli helped participants give accurate descriptions of themselves because memories were triggered that helped to support their responses. A similar study was performed by Eustache et al (2013), involving 16 participants with mild to severe Alzheimer's disease and a control group of 16 age-matched adults. They used a shortened version of the TST, asking both groups of participants to orally produce 10 'I am…' statements, repeating the procedure after a two-week period. They reported no significant difference between the two groups, suggesting that their participants with Alzheimer's disease retained as complex a sense of identity as people without dementia. Eustache et al also reported that their results were comparable after the two-week interval and the Measure of Self has replicated these findings.

Thirdly, for Quality of Self, test-retest reliability was demonstrated because there were no significant differences between scores at Time 1 and Time 2 for both groups. The scores for the control group were slightly higher than for the dementia group, but this was not a significant difference. Conversely, Addis and Tippet (2004) reported that their participants with Alzheimer's disease generated a significantly higher percentage of abstract responses for the TST than the control group. Addis and Tippet interpreted this as showing that participants with Alzheimer's disease showed a 'changed' quality of identity compared with the control group, implying that the group with Alzheimer's disease showed an impaired sense of identity. However, it is not clear from their report what they meant by 'abstract', apart from linking it with vaguer and less definite responses. For the Measure of Self, abstract responses were considered to require more cognitive input than concrete responses. Results for the Measure of Self suggest that all participants were able to think about aspects of self such as traits and personal characteristics because they were able to give definite 'Just like me' and 'Not at all like me' responses. This is reinforced by participants with dementia making comments about their choice of 'Just like me' traits, including participants with more severe dementia. herefore, this study has again demonstrated that providing visual stimuli helps people think about aspects of themselves that are not facilitated by simply asking for statements, such as in the TST, and that the responses they give are reliable because they do not change after a two-week interval.

Episodicity scores also showed no significant difference between Time 1 and Time 2. Scores for participants with dementia were lower than the control group, which confirms previous findings (e.g. Addis and Tippet, 2004, Green et al, 1995) that asking participants to remember events, rather than allowing memories to come to mind spontaneously, is more difficult for people with dementia than people without memory impairment. Both Study 1 and Study 2 have demonstrated that participants can spontaneously describe memories associated with stimuli during the Matching Phase of the Measure of Self; thus the process of looking at images and thinking about aspects of self has been shown to bring autobiographical memories to mind. This suggests that people with dementia do not lose important self-knowledge and the results of Study 2 have demonstrated that their strength of self can be comparable to that of

people without dementia, even if their ability to recall detailed episodic memories when asked to do so is impaired.

5.8.2 Convergent validity

The results of testing for convergent validity were less uniform. For Strength of Self there was good correlation between the TST and Measure of Self, but poor correlation between TSCS-II and the Measure of Self. This is demonstrated by the mean scores for the TST and the Measure of Self being high, both were in the top 75% of possible scores, whereas the mean scores for the TSCS-II were below 50%. This may be because the descriptive statements that formed the identity component of the TSCS-II were not relevant or meaningful for the participants in this study, whereas generating their own statements for the TST provided a more meaningful description of self, and being able to choose from a set of images relevant for this age group, provided by the Measure of Self, also enabled the participants to describe themselves without difficulty. For Complexity of Self there was no significant correlation between the two sets of subcategories generated by the TST and the Measure of Self. The numbers of subcategories were generally fewer for the TST than for the Measure of Self, again suggesting that self-generation is more difficult than responding to cues provided by stimuli. For Quality of Self there was evidence of a moderate convergence between the Measure of Self and the TST but as stated above, the small number of participants may have skewed the results.

5.8.3 Observational Framework

The observational framework was shown to be useful when used with participants with communication difficulties. Generally, participants were able to say ‘yes’ or ‘no’, or nod or shake their heads, but the checklist helped to confirm the accuracy of how ‘like them’ the stimuli were. Despite having problems with conversation, participants understood what to do with the stimuli, and were able to consider the three ‘like me’ responses. Their ability to successfully talk about some of the stimuli was surprising, and may demonstrate the benefit of using visual cues as a way of enhancing the verbal and expressive abilities of people who otherwise may not be able to communicate verbally.

Thus, with regard to piloting the observational framework, this study has shown that there are common gestures and behaviours that people use to express

themselves that can be easily understood by people observing them. Also, the stimuli presented in the Measure of Self not only cued memories, but also helped people express themselves verbally by only requiring them to say one or two words in response to an image, rather than having to construct sentences.

5.9 Summary

With reference to the two study aims stated in the introduction to this chapter, the results of the investigation into the psychometric properties of the Measure of Self are promising. The outcome measures that were developed for the Measure of Self can be reliably compared over time periods, and with other tests of self and identity. Good test-retest reliability has been demonstrated and some convergent validity was shown with the TST, but less with the TSCS-II. The participants with dementia were judged to be in moderate to severe stages of the condition, and all were able to complete the Measure of Self with no difficulty. Furthermore, their results were comparable with, and in some cases scores were higher than control participants. It is acknowledged that numbers of participants were small but the results of Study 2 provide evidence to support the view that people with dementia can be helped to accurately describe their sense of self and the Measure of Self is a suitable tool to investigate this further.

6. General Discussion

Ask not what disease the person has, but rather
what person the disease has.
(Sacks, 1995, p. xi).

6.1 Introduction

This chapter begins by drawing together findings from preceding chapters in relation to the stated aims of the thesis and existing literature. It presents findings in the context of previous studies, and highlights results that are novel and that add to the current understanding of self in dementia. The final sections of the chapter consider limitations of the studies, possibilities for further research using the Measure of Self, and implications for clinical practice. The chapter concludes with consideration of how useful the findings have been with regard to the aims of the thesis.

6.2 Aims of thesis

The overarching aim of the thesis was to develop a new objective measure of self designed specifically for people living with dementia that can be used to evaluate psychosocial interventions and inform care practices. Work for the thesis has drawn on research originating from different disciplines in order to discover which aspects of self can be investigated experimentally, using methods that enable people with cognitive impairment to express these aspects themselves. Methods that were considered to be most useful were taken from cognitively focussed experimental studies and socially focused investigative studies. The chosen methods were combined and adapted to facilitate the expression of retained aspects of self in people with dementia.

A new conceptual framework of self was created (figure 6.1) that was used during all stages of development of the Measure to ensure that all the aspects of self relevant to people with dementia were covered by the new Measure of Self.

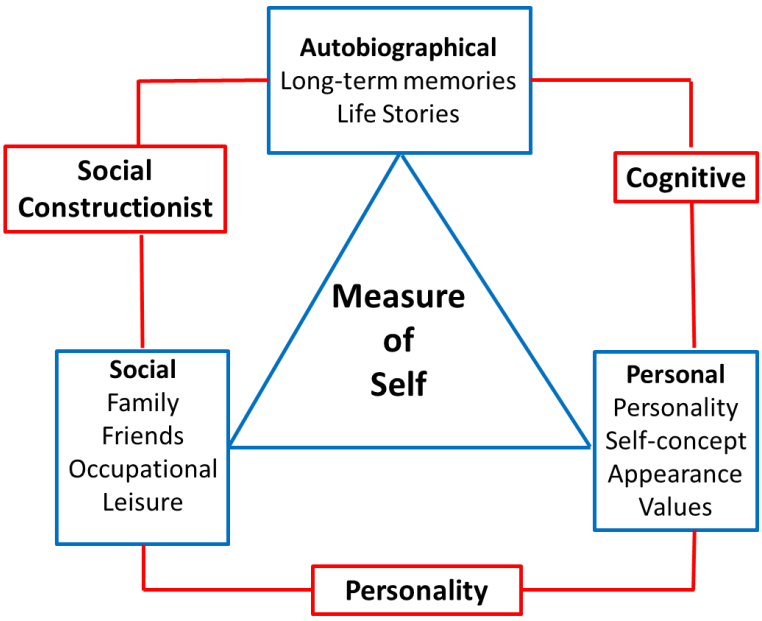


Figure 6.1 New Conceptual Framework of Self

This illustrates how the different approaches were linked to the multiple aspects of self. (Note that in previous versions of the diagram the central title was 'Self Test'. This was changed to 'Measure of Self' because 'Test' was considered to imply a scored activity with correct and incorrect answers).

An additional requirement of the new measure was that it should demonstrate robust psychometric properties when administered to people with dementia. This requirement was addressed from the beginning of the development of the new measure by following a recognised 7-stage development process (Figure 4.1). This included the prerequisites of consulting expert advisors and performing a pilot study to test the suitability of materials and methods of administration of the Measure of Self before testing it for reliability and validity.

6.3 Main findings

The following sections discuss the results of the Pilot Study, Study 2 and Study 3, by assessing them in relation to the aims of the thesis and previous studies involving people with dementia.

6.3.1 A new multifaceted model of self

It was proposed at the start of this thesis that a multifaceted view of self would be most appropriate for explaining and understanding what happens to the sense of self of a person with dementia. The Measure of Self has been shown to be effective in covering the different aspects of self that were identified in the

literature review, and has integrated more measurable aspects of self into a single model than previous investigators have done. The Pilot Study and Studies 2 and 3 demonstrated that all participants were able to describe themselves holistically, i.e. they chose stimuli from between 7 and 10 subsets as being 'Just like' them. They considered aspects related to their bodies, clothes, house, relatives, friends, reputation and occupations, confirming the continued relevance of James's definition of self in section 1.2.

Moving on to studies reported in the literature review that considered self as multifaceted, Fargeau et al (2010) looked for change in three aspects of self associated with dementia (material, spiritual and social) by asking carers of people with dementia eight questions concerning these aspects of self. However, there were two contentious aspects of their study: i) the researchers were looking for *change*, not *retained* aspects of self, and ii) they used proxy reports so could not know for certain what participants thought about themselves. They reported that the majority of their participants demonstrated impairment in at least one aspect of self, but this meant that for some of their participants, two out of three aspects remained, but these conserved aspects of self were not considered. They also reported that if one aspect was affected, this was the Social Self. This could be the result of stigma associated with dementia, and 'malignant social psychology' (Kitwood, 1997b, section 1.3) rather than fundamental change in the person's sociability.

Gil et al (2001) considered a larger number of aspects of self, which they termed as 'self-awareness'. This included awareness of one's body, life history, continued identity, past and present projects, and moral stance. However, they only used 14 questions to cover all of the aspects, meaning that some aspects were assessed by one or two questions. For example, a participant's emotional state was judged by "Do you feel rather happy or unhappy? Why?". Responses were scored as 'relevant' (2 points), being 'partly correct' (1 point) or 'incorrect' (0 points), but as it is difficult to assess how correct a person is if s/he says s/he is 'rather unhappy', for this question, Gil et al consulted a family member to check the accuracy of the participant's emotional state. As previously stated, the accuracy of relatives' accounts is questionable, and asking someone else devalues the belief of the person with dementia. Furthermore, several of the questions that Gil et al used asked for opinions, rather than self-descriptions.

For example, “Is it a good thing or a bad thing to tell a lie? Why?”. Again, it is difficult to assess the response; a person may *say* it is a bad thing to lie, but not always be truthful when talking to other people, therefore the person may be given a score of 2 for relevance, but there would be no way of knowing if the reply was actually partly correct (because the person knows it is wrong to lie but does not act according to this belief). Nevertheless, Gil et al concluded that a core deficiency caused by Alzheimer’s disease was an inability to maintain “attention to life”. The meaning of this is wide ranging, therefore difficult to know what the researchers meant precisely. If they were including orientation to surroundings, and awareness of other people, it is possible to draw the opposite conclusion from the Pilot Study and Studies 2 and 3; all the participants were aware of where they were, what they were being asked to do, what had happened to them in the past, etc., suggesting that many of their aspects of self-awareness were intact.

A related issue that emerged from the findings was the status of the moral aspect of self. Findings suggested that having good moral traits was important to many of the participants. Results from the Pilot Study showed that 19 out of 20 participants considered themselves to be honest and helpful, and 16 out of 20 said they were thoughtful, had good manners and were punctual (all these traits were chosen as ‘Just like me’). These could all be described as desirable moral traits; often participants said “*I like to think so*”, *“I try to be” or “I hope so”* when considering these statements; one participant said about good manners *“Yes, definitely, we were taught them as kids”*. By investigating this further, it was discovered that these results add support to a study by Strohminger and Nichols (2014) who proposed the ‘essential moral self hypothesis’ and reported that moral traits were considered to be the most important aspect of the self. The longevity and strength of the moral self were investigated in a later paper by Strohminger et al (2017) who advocated a distinction between the self and the ‘true self’ which they described as a subset of characteristics that are considered to be positive and moral “making people who they really are, deep down” (Strohminger et al, 2017, p 551). A similar concept is proposed by Lindemann (2014) who calls it ‘second nature’, which is the sense of right and wrong that is learnt through ‘decent upbringing’ (p.13). Thus, the results generated by the Measure of Self have provided evidence to support the

proposed strength, longevity and importance of such moral characteristics. For the Pilot Study, five participants chose a moral trait as their most important stimulus, and for Study 2, four moral traits were chosen as most important across Time 1 and Time 2 by the participants with dementia.

It is possible that the desirability and longevity of moral traits can be accounted for by taking a social constructionist stance, which relates self to the social and cultural values of the communities in which people are living. For example, moral traits can be related to Self 1, proposed by Sabat and Harre (1992), defined as the personal identity that underlies the publicly presented personae (section 2.6.4) which is considered robust and resistant to change. Results from the Measure of Self also demonstrated that social and relational aspects of self were important to participants, such as family history and past occupations. These findings relate to Sabat's Self 3, defined as the multiple personae that people present to others, that are supported by the help and cooperation of others (Sabat, 2002, 2005). For the Pilot Study, nine participants chose a family role as their most important stimulus, and for Study 2, two participants chose a family role, and two an occupational role as being most important. These results also emphasise the importance of carers and relatives of people with dementia continuing to show interest in their families and life histories, as highlighted by Surr (2006), in order to maintain self.

The importance of hobbies, crafts, and sporting activities was also demonstrated by the Measure of Self. Participants in all the studies chose a wide range of activities as being 'Just like me', and six participants in the Pilot Study chose some form of activity as their most important stimulus. These results support the findings of Frazer et al (2012) who reported that continuing to take part in hobbies and leisure activities helped women with dementia maintain their identity and independence. The ability to perform these activities may become impaired because of physical and/or visual impairments as people age, but participants in the three studies were still able to talk about activities that they used to enjoy.

Overall, the results of the Pilot Study and Studies 2 and 3 have demonstrated the validity of considering self as multifaceted, and that providing a wide range of visual cues to help people recognise these aspects of themselves is more effective for people with dementia than simply asking questions. This point is

returned to in the following section which will discuss the value of looking for preserved abilities, rather than deficits, and how and why this can be facilitated by using cues.

6.3.2 Looking for preserved abilities

The Measure of Self was designed with the objective of identifying preserved cognitive abilities of people with dementia in order to demonstrate retained aspects of self, and to not expose participants to feelings of having failed to do what was asked of them. This is unlike other cognitive tests which have been designed to identify deficits.

An important finding from using the Measure of Self is that providing visual cues representing 'I am' statements enhanced the ability of participants with mild to severe dementia to recall aspects of themselves that were important to them. All the participants demonstrated a strong sense of self, with scores ranging from 69% to 97% across all three studies. There were similar scores for the control group in Study 2, ranging from 75% to 94%. Scores for strength of identity were reported in studies by Addis & Tippet (2004) and Jetten et al (2010) who used versions of the 'I am' test, but it is not possible to directly compare figures because different methods of administration of the tests were used. However, it is possible to say that Addis & Tippet reported that their participants with mild Alzheimer's disease showed *weaker* identity strength than their control group, and Jetten et al reported that their participants with dementia showed *lower* identity strength than their control group. However, Eustache et al (2013), using similar methods to Addis & Tippet, reported that participants with mild to severe Alzheimer's disease demonstrated *preserved* identity compared with their control group, seemingly opposing the results of Addis & Tippet. Eustache et al suggest that this may be due to their methods of responding to questions being simpler than Addis & Tippet, i.e. Eustache et al used a dichotomous true *or* false scale rather than a 5-point true *to* false scale; participants with impaired comprehension may have been drawn to the central, vague rating of neither true or false.

However, it is likely that the most significant reason for the effectiveness of the Measure of Self was the use of visual stimuli in the form of written statements illustrated by photographic images in combination with a simplified response

scale. These stimuli prompted *recognition* of aspects of self that were important to participants, which was more effective than asking them to freely *recall* such aspects in the standard 'I am…' task. Furthermore, the line of reasoning that led to the development of the stimuli took account of several memory related models and phenomena. Firstly, presenting visual images acting as prompts relates to the phenomenon of multimodal perceptually cued autobiographical events (Karlsson et al, 2013), by which events are remembered by combining cues (such as words and pictures) that trigger strong feelings of travelling back in time. Secondly, perceptual cues can trigger direct retrieval (Conway & Pleydell-Pearce 2000, section 2.2.2), which activates retrieval of memories without the need for a cognitively demanding search process, i.e. generative retrieval. Thirdly, using photographs meant that cues could reference a particular time period, i.e. the reminiscence bump era of the participants (section 2.2.3), and correspond to time periods relevant to the Self Memory System, such as activities at secondary school, or sporting events attended with parents or children (section 2.2.2). Participants frequently made comments relating to being good or bad at sports at school, or going dancing, or to the cinema when they were young adults. These findings coincide with results of the study by Piolino et al (2003) which demonstrated that remote memories were better preserved than recent ones in their participants with Alzheimer's disease.

Two studies identified in the literature review used perceptual cues for triggering memories and conversation. Ilem et al (2015) presented each participant with one photograph of him or herself taken during middle age and one recent photograph. More participants recognised the earlier photographs rather than the recent ones. The second study by Cohen-Mansfield et al, (2010) demonstrated that people with dementia became highly engaged with cues or stimuli that were personally significant. Cues that related to family relationships and past occupations and hobbies were most likely to result in engagement, which was measured in terms of type of attention paid to the stimulus, and length of time spent engaging with the stimulus. Both studies demonstrate the value of using visual cues, corroborating the findings from the Measure of Self.

With reference to the Self Memory System (section 2.2.2) personally significant cues can provide a direct route to episodic memories, and visual cues prompt

memories that produce stronger feelings of traveling back in time than non-perceptual cues (Karlsson et al, 2013). This leads to the hypothesis that personally significant images will invoke memories with more episodic specificity than non-significant, non-perceptual cues. This hypothesis was tested during the Sorting and Memory Phase of the Measure of Self. It was envisaged that the process of choosing a stimulus that was 'most important' would result in one 'I am' statement that was highly significant to the participant, which would quickly trigger a detailed memory related to the stimulus. The results demonstrated that the majority of participants in the Pilot Study and Study 2 recalled memories related to the most important stimulus, but the levels of detail that the memories contained were mixed, i.e. more memories were generalised (semantic) in nature than were specific (episodic). However, some of the memories that scored 2 on the episodicity rating scale contained specific details, but not specific enough in time or place to score 3, suggesting that the stimuli were helping the participants to remember events, but not to vividly relive them. This corresponds with results from studies by Dalla Barba (1997), Piolino et al (2003), and Martinelli et al (2013) which demonstrated that participants with dementia had impaired episodic recall, but semantic recall was comparable with control groups. Other studies (i.e. Ally et al, 2009, Hudon et al, 2009, and Irish et al, 2011b) demonstrated that both types of memory were impaired in participants with Alzheimer's disease and mild cognitive impairment. However, these studies were based on encoding and recall tasks in which standardised stimuli that participants were asked to remember were not significant to them. Given that forming new memories is especially difficult for people with cognitive impairment, the results may not have been truly representative of their abilities.

Considering the predominantly semantic nature of memories recalled during performance of the Measure of Self, studies reporting impairment in episodic recall (e.g. Piolino et al, 2003, Irish et al, 2011a) suggest that this impairment contributes to loss of self because people with dementia have an 'impoverished capacity' (Irish et al, 2011a) to relive visual imagery, and the emotions associated with vivid memories. Piolino et al (2003) concluded that their participants with Alzheimer's disease experienced a deficit in autonoetic consciousness meaning they 'just knew' that an event had occurred, rather than 'remembering' the event in detail. Thus, loss of functions, or deficits, are

emphasised, rather than considering functions that remain. However, Tippet et al (2018) demonstrated that participants with Alzheimer's disease and mild cognitive impairment generated more autobiographical memories that were semantic in nature than memories that had episodic detail, but they still had strong belief in the persistence of their core self. The authors suggest that self-belief persists in spite of impaired episodic memory if semantic memory is intact. Alternatively, it is possible that people are experiencing autonoetic consciousness when they recall memories, but are not able to express this aspect of the memories.

Moving on to the experiential, or 'being in the world aspects' of self-awareness, studies reported in the review suggested that people with dementia had impaired awareness of their memory problems but this was associated with a more positive and definite sense of identity (e.g. Naylor & Clare, 2008), which may act as protection against awareness of more serious cognitive problems to come (Morris et al, 2014). However, results from the Measure of Self showed that many participants described themselves as forgetful, with some saying that this was because of their condition (those who knew that they had been diagnosed with some form of dementia). One participant was able to distinguish between his current forgetfulness: *"I put stuff away and I can't remember where I have put them, and go round looking. I spend hours sometimes trying to find it"*, and being able to remember events from the past: "*I'm thoughtful. Well, I do think a lot about the past, about when I were young and stuff, you know. I'm always remembering, yep".*

Regarding physical appearance, all participants were able to describe their height and build (e.g. they understood the idea of 'having a large waist), and knew what their hair colour had been. Again, one participant was aware of changes to his appearance resulting from his diagnosis of dementia: *"Only because of this* [dementia], *not working like I used to, so I'll choose* [points to 'Just like me' response]. *No, I normally didn't have a large waist but because of this* [dementia] *I eat a lot of biscuits and what have you."* These results concur with those of Clare et al (2008) who demonstrated retained awareness of sense of self and suggested that retained awareness of multiple aspects of self outweighed unawareness.

Combining all the results together has demonstrated that the stimuli provided by the Measure of Self, and methods of administration have identified preserved abilities and awareness of self that previous experimentally focused studies have not found, or have disregarded because they were looking for deficits. The following section concerns observable aspects of self that were demonstrated with participants who had communication difficulties.

6.3.3 Findings from the observational study (Study 3)

The findings from Study 3, piloting the observational checklist, were surprising because, although care staff had suggested these participants were unlikely to speak, all three participants were able to express themselves verbally. Their speech was still limited but they were more fluent than when talking during day-to-day conversations. During 'normal' conversation it was possible to see from their facial expressions that remembering what people had said to them, and thinking about what to say in response, was difficult for them. But when the researcher showed them the stimuli in many instances words seemed to come spontaneously, suggesting that the visual cues bypassed the cognitive processes required for producing speech. The researcher also noted that each person had their own ways of indicating some of the responses. For example, Evelyn held a hand out, keeping it flat, but moving it from side to side to indicate 'A bit like me' responses. Pamela, who had the most severe speech impairment, showed more facial expressions than Daphne and Evelyn, suggesting that she was learning to use these expressions to help her communicate. Thus, performing the Measure of Self demonstrated that all three participants had preserved abilities that they did not usually show, and that performing the Measure enhanced their access to these abilities.

These gestures and facial expressions are examples of behaviours that can be described as aspects of embodied selfhood Kontos (2004). These include signs of social etiquette and expressions of caring that become elements of bodily habits and expressive gestures. People with severe dementia have been observed to continue to use bodily actions to communicate when they find speech difficult; the important point is that these gestures and expressions are common to all people with and without dementia, therefore should be recognisable to carers of people with dementia if they are helped to look for them, and people with dementia are encouraged to express them.

Another aspect of selfhood is second nature (see also section 6.3.1) which is demonstrated by expressions, responses and recognitions that are automatic, with no conscious thought required. Lindemann (2014) has proposed that ultimately Alzheimer's disease destroys a person's second nature, which is worsened if they are treated as nonpersons; "nothing more than a body to be washed, clothed, and fed" (p.19), but if their personhood is respected by the people who care for them, they may continue to have some capacity to "give bodily expression to their mental states".

To summarise, recruiting participants with speech impairment and quite severe dementia not only demonstrated that the Measure of Self can be used effectively with them, but also indicted that memories can be triggered which can help people find words. If words cannot be found, performing the Measure of Self has demonstrated that people with severe dementia can continue to give indications of the person behind the disease.

6.4 Limitations of findings

The main limitation of the project was the small sample size for Study 2; test-retest reliability was demonstrated but validity of the Measure of Self could not be fully demonstrated. The small sample size reflects the current challenge of recruiting people in care homes. It was envisaged that the sample size would be comparable to the Pilot Study, but it was not possible to recruit enough people with more severe impairments to fully test the observational framework. The first contact at care homes was usually the managers who acted as gatekeepers, who may have made incorrect assumptions about the responsibilities associated with participating in research studies, and the input required from care staff. The care home from which four participants were recruited had an activities coordinator who was more receptive to being involved in the research study, but the researcher noted that care homes were increasingly short of staff, and managers were concerned that there would be no one to help the researcher find suitable volunteers, or have time to explain what the research would involve. People with cognitive impairment are understandably reluctant to volunteer for something that they think will be difficult for them, or they may think they will not be able to make a useful contribution to the research study. The information sheets and consent forms that participants were asked to look

at and complete may have made the procedures seem daunting, although this was helped when the researcher went through the forms with them.

However, the underlying ethos of this research project was to include people with more severe dementia who tend to be excluded from research involving interventions that could help improve their quality of care. Therefore, a suggestion for recruiting from care homes would be for the researcher to take time to become known to residents and staff, perhaps joining in a regular activity. This would enable the researcher to become familiar with the layout and routines of the home, as well as getting to know the residents, and so need less help from the staff.

Another limitation was that the participants were restricted to people with English as a first language, and the stimuli were limited to British cultural beliefs and activities. However, in future the 'I am' statements could be translated into different languages and culturally appropriate statements, and images changed to reflect the social and cultural activities and beliefs of a wider community of participants.

6.5 Implications for future research and practice

The most important requirement for future research is to test the Measure of Self as a means of assessing psychosocial interventions. This addresses the expressed need for improved outcome measures that let people with dementia have a voice (Moniz-Cook, 2011). A starting point for interventions would be reminiscence activities and life history work that focus on the self.

The findings of this thesis also suggest other ways of using the Measure of Self, in practice, and for future research. As mentioned above, the Measure of Self could be adapted for different cultural groups which would enable its reliability and validity to be tested over larger populations. It could be used in care homes and cay care centres to help staff find out about past lives of residents, and as starting points for conversations and interactions with staff and other residents. Because the Measure of Self relies on images and simple 'I am…' statements, it could be developed as an app for use on tablets and computers. Using a touch screen, individuals could move images to the appropriate 'like me' response. This would not need to be used on a table top, and people who are unable to sit upright at a table could be helped to use a tablet.

Considering theoretically focused research, the Measure of Self could be used to investigate the episodic/autonoetic and semantic/noetic nature of memories. For example, to add to the findings of the study by Tippet et al (2018) who hypothesised that sense of self can be supported by semantic memories, but used generative retrieval as a means of eliciting autobiographical memories. It would be useful to compare results from the Measure of Self against results from the 'self-persistence' interview used by Tippet et al, to see if performing the Measure of Self affects the explanations people with Alzheimer's disease provide for their belief in self-persistence. Tippet et al reported that participants with Alzheimer's disease scored well on measures of belief in self-persistence, but their explanations were 'less sophisticated' (Tippet et al, 2018, p. 1) than the control groups, and when asked to talk about their life story the participants with Alzheimer's disease talked about fewer life events than the other groups, i.e. mostly semantic memories. Therefore, it would be interesting to investigate whether performing the Measure of Self helps people with Alzheimer's disease provide more details about their selves and their life histories, i.e. produce more episodic memories. Furthermore, when performing the first 'Matching' phase of the Measure of Self, participants often make spontaneous comments about why they had chosen a 'Just like me' or 'Not at all like me' response; sometimes they recounted a specific incident that they remembered. It would be possible to take note of the comments, and rating them as semantic or episodic may provide an indication of the proportion of support given by these memories.

6.6 Conclusion

This thesis has achieved its aim of developing a new Measure of Self that can be used successfully with people with dementia because i) it takes account of multiple aspects of self, therefore is more likely to identify aspects of self that are retained than previous measures which are more narrowly focused, and ii) the content and methods of administering the measure are more sensitive to the abilities of people with dementia than existing measures that were designed for use with people with no cognitive impairment. Specifically, the combination of 'I am…' statements and related images has been shown to assist direct recall of self-related memories, rather than the effortful, generative recall of other measures. This has not been demonstrated before in people with dementia, and suggests that providing cues ameliorates the deficits reported in previous

studies. Furthermore, the Measure of Self gives voice to people with dementia themselves, instead of asking for the opinions of relatives and carers, and does not require confirmation of what participants say. In addition, performing the Measure helped people with quite severe dementia and communication difficulties express themselves verbally, as well as demonstrating the importance of physical gestures and facial expressions. Thus the Measure of Self provided a new means of investigating retained self in people with dementia. The Measure was carefully and rigorously developed so that it that can be tested further as a means of evaluating psychosocial interventions, that in turn may encourage new practice in the care of people with dementia and promote good quality of life for them, by helping carers to know and respect the person and not fear the disease.

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Appendix I: Pool of 23 Measures with Appraisal Scores

Name of measure	Reliability general	Validity general	Reliability/ Validity pwd	Used with pwd	Type of dementia	Severity of dementia	Number of Ppts	Comments	Score
Autobiographical Memory Interview (AMI) Kopelman et al 1989	Reliability = 0.83 to 0.86	'Positive' concurrent validity with 'Famous Personalities' test and the 'Crovitz Test'. Differential validity: 'discriminated significantly' between 'amnesic' ppts and controls.	No	Yes	VaD	'moderate'	3	Useful because I can use a variety of ways of prompting memories, e.g. picture and sounds of children in playground to prompt memories of school; popular singer and song to prompt teenage memories.	**5**
Addis & Tippet (2004)			No	Yes	AD	Mild to mod AD. MMSE: 13 to 24.	20	Emphasise personal semantic memories?	
AMI-Extended Naylor & Clare (2008)			No	Yes	Mixed dementias	Mild to mod. MMSE = 16 to 29	30	Extended = additional 'middle-age' time periods	**5**
Subramaniam et al (2014)			No	Yes	Dementia	Mild to mod. re CDR	24		
Name of measure	**Reliability general**	**Validity general**	**Reliability/ Validity**	**Used with**	**Type of dementia**	**Severity of**	**Number of**	**Comments**	**Score**

			pwd	pwd		dementia	Ppts		
Autobiographical Interview Levine et al (2000)	Inter-rater reliability 0,79 to 0.96	Construct validity c.f. AMI = 0.68	No	No			30	Similar questions to AMI with conditions for retrieval support specified; e.g. "What was the weather like?" "Where you with other people?"	**3**
Thinking About Life Experiences Scale (TALE) Bluck & Alea (2011)	Internal consistency = 0.86 Test-retest reliability = 0.70 to 0.79	3 highly inter-correlated factors (av. 0.52) Average total item correlation = 0.54 External validity = 'good' Construct validity = 'strong' c.f. measures of self-esteem	No	No			306	28 questions. Relates to functions of memories, e.g. "I want to feel the same person I used to be"; "I want to share memories with friends".	**4**
Brooks and McKinlay Personality Inventory Brooks & McKinlay (1983) Petry et al (1988) Aitken et al (1999) Talassi et al (2007) (Italian version)		Concurrent and predictive validity demonstrated for ppts with closed-head injury.	No Test-retest reliability for all items =	No Yes (proxy) Yes (proxy) Yes (proxy)	 Spouses of people with DAT AD + VaD Dementia	 Mean MMSE = 10.9 Mean MMSE = 7.1 + 7.5 Mean MMSE = 17.7	 30 60 (AD) 39 (VaD) 15	36 statements, e.g. "Out of touch"; "Relies on others"; "Fond of company"; "Even tempered". Care giver ratings Care giver ratings Care giver ratings	**3**

			0.55 to 1.0						
Twenty Statements Test (TST) Kuhn & McPartland (1954)	Test-retest reliability = 0.85	Coefficient of reproducibility = 0.9						20 'I am..' statements	
Addis & Tippet (2004)				Yes	AD	MMSE = 13 to 24	20	Adapt by using verbal responses and visual prompts	**4**
The Oral I-AM Test (10 statement version of TST) Eustache et al (2013)			Test-retest reliability demonstrated	Yes	AD	Mean MMSE = 14	16	10 'I am..' statements	**5**
The 3-I Test (adapted from TST) Duval et al (2012)				Yes	SD	Early to mod. SD. MDRS mean = 117	8	3 x 5 statements 'I am..', 'I was….', 'I will be…'	**3**
Tennessee Self Concept Scale – II (TSCS-II) Fitts 1965 Marsh & Richards (1988)	Series of exploratory and confirmatory factor analyses	Convergent + discriminant validity determined c.f. Self - Description Questionnaire III	No	No			343	Large number of descriptive statements, e.g. "I have a healthy body"; "I feel happy most of the time"; "I can no longer think straight".	
Addis & Tippet (2004)			No	Yes	AD	MMSE = 13 to 24	20	Use verbal responses and visual prompts	**4**

IMAGE Test Eustache et al (2013) (adapted from TSCS-II for people with AD)			Test-retest reliability demonstrated	Yes	AD	Mean MMSE = 14	16	24 descriptive statements, e.g. "I'm naturally cheerful"; "I'm quite serious minded" (possible 'gold standard' for comparison?)	**5**
Self-Consciousness Questionnaire (S-CQ) Gil et al (2001)			Inter-observer reliability = 0.96 Test-retest reliability = 0.73	Yes	AD	MMSE = 10 to 21	18	14 statements. Multiple aspects of self: identity, cognitive impairment, body state, prospective memory, e.g. "do you feel happy or unhappy? Why?"; "What will you do when you have finished talking to me?"	**3**
Questionnaire of Self-Representation (based on S-CQ) Duval et al (2012) Eustache et al (2013)			No No	Yes Yes	SD AD	Mean MDRS = 117 Mean MMSE = 14	8 16	Selection of positive and negative statements about the self, e.g. "I'm self-conscious about the way I look"; "I like to spend time with other people".	**4**
Name of measure	**Reliability general**	**Validity general**	**Reliability/ Validity pwd**	**Used with pwd**	**Type of dementia**	**Severity of dementia**	**Number of Ppts**	**Comments**	**Score**

Self and Identity in Dementia Questionnaire Cohen-Mansfield et al (2000, 2006, 2010)	Internal consistency = 0.83 Test-retest reliability =0.86		No	Yes (3 studies)	Dementia	Mean MMSE = 8.7 Mean MMSE = 10.58 Mean MMSE = 7.2	38 93 193	> 20 questions (depending on number of roles described) 'Self and Identity'= professional, family and social roles; hobbies and leisure activities; personal attributes, traits and achievements. Participants rate importance of roles and activities.	**5**
Self-Consciousness Scale (SCS) Fenigstein et al (1975) Scheier & Carver (1985) (revised SCS)	Internal consistency of 3 subscales = 0.8 Test-retest reliability = 0.75	Factor analysis and inter-scale correlations	No	No			298	23 questions Assesses private and public self-consciousness e.g. beliefs and feelings c.f. behaviour, mannerisms and expressive qualities, e.g. "I reflect about myself a lot"; "I'm usually aware of my appearance".	**3**
Name of measure	**Reliability general**	**Validity general**	**Reliability/ Validity pwd**	**Used with pwd**	**Type of dementia**	**Severity of dementia**	**Number of Ppts**	**Comments**	**Score**

Physical Self-Concept Scale for Older Adults (PSCS-OA) Hsu & Lu (2013)	'Preliminary' reliability Confirmatory factor analysis	Content validity determined by pilot study. Construct validity c.f. measure of subjective well-being = 0.65 + 0.75	No	No (2 studies)			10 (pilot) 233	18 statements concerning physical characteristics and abilities, e.g. "I am satisfied with my weight"; "My body is stiff"; "I get ill a lot".	**3**
The Relational, Individual and Collective Self-Aspects Scale (RIC) Kashima & Hardie, (2000)	Series of exploratory and confirmatory factor analyses.	Convergent validity c.f. 8 existing measures of self. Divergent validity c.f. 2 scales of identity.	No	No (2 studies)			170 216	10 questions each with 3 possible responses, e.g.: "I regard myself as: -An individual. -A good wife/ husband/ partner/ friend. -A good member of my group.	**3**
Self-Concept and Identity Measure (SCIM) Kaufman et al (2015)	Test-retest reliability = 0.93 Internal consistency = 0.7	Interclass correlation coefficient = 0.88 'Adequate' construct validity = 0.66 to 0.78	No	No			536	30 questions To assess problematic identity functioning in clinical populations, e.g. "I know who I am"; "I feel empty inside, like a person without a soul"; "I have been interested in the same types of things for a long time".	**2**
Name of measure	**Reliability general**	**Validity general**	**Reliability/ Validity pwd**	**Used with pwd**	**Type of dementia**	**Severity of dementia**	**Number of Ppts**	**Comments**	**Score**

Social and Personal Identities Scale Nario-Redmond et al (2004)	Internal consistency of 0.8 for personal identity scale and 0.79 for social identity. Test-retest reliabilities of 0.77 for personal, and 0.82 for social scales	Six studies demonstrated criterion and construct validity c.f. similar measures of identity	No	No (6 studies)			>1000	16 statements, 8 per subscale, e.g. "The similarity I share with others in my group", and "My need to be completely distinct and unique from everyone else"	**3**
Life Orientation Test (LOT) Scheier & Carver (1985)	Internal consistency = 0.76 Test-retest reliability = 0.79	Convergent and discriminant validity demonstrated	No	No			150	12 statements Assess dispositional optimism, e.g. "In uncertain times I usually expect the best", and "I don't get upset too easily".	**3**
Rosenberg Self-Esteem Scale Rosenberg (1965) Martin-Albo et al (2007)	'Good' internal consistency and test-retest reliability	High construct validity c.f. other measures of self-concept	No	No			420	10 statements Relate to a person's general feelings about him/herself, e.g. "On the whole I am satisfied with my life", "All in all, I am inclined to feel that I am a failure".	**3**
Name of measure	**Reliability general**	**Validity general**	**Reliability/ Validity pwd**	**Used with pwd**	**Type of dementia**	**Severity of dementia**	**Number of Ppts**	**Comments**	**Score**

Sense of Belonging Scale Hoffman et al (2002-2003) Tovar & Simon (2010)	Internal consistency = 0.9	Convergent validity established c.f. one measure of goodness of fit (CFI)	No	No			463	26 statements To assess sense of belonging with university students, e.g. "I feel comfortable talking in groups", "I have made friends with people I have met in groups".	**3**
Personal Self Concept Questionnaire (PSCQ) Goni et al (2011)	Internal consistency = 0.85	Content validity determined by 4 experts	No	No			1135	22 statements To assess 4 aspects of self-concept: self-fulfilment, honesty, autonomy and emotions, e.g. "I feel proud of how I am managing my life", "I am a man/woman of my word"	**3**

CDR = Clinical Dementia Rating, MDRS = Mattis Dementia Rating Scale

Appendix II: Notes from conversations with service users

(Experts by Experience)

Three residents of a care home specialising in dementia care

Resident 1

Date: 22.11.13 **Name:** 'Eric' **Age:** 92

1. What do you think a sense of self or a sense of identity means to you?

I have had a good life.

I am pleasant with people.

I am a manager, have a desire to control and do things.

For example:

- **Personal characteristics:** happy with people
- **Jobs you do or used to do:** office manager
- **Family roles – mother, father, sister, brother, grandparent:** 6 children, 4 girls, 2 boys
- **Hobbies, activities or interests:** have been fortunate, not annoyed by other people or been annoying to them

2. When you think of yourself, what images come to mind?

I am at peace.

Good family life – happy to talk about family

Not easy to entertain – "silly old man"

Taken opportunity of good luck

3. What words describe you as a person?

Manager, competent, knew job, expert

Happy man

The Boss – decent, nice, everyone knew me

Ridiculously comfortable

4. What kinds of possessions are most important and what do they remind you of?

My flat is full of bits and pieces such as family photographs – children, grandchildren and great-grandchildren, radiogram.

Resident 2

Date: 18.10.13 **Name:** 'Sandra' **Age:** born 1936

1. What do you think a sense of self or a sense of identity means to you?

Makes me feel that someone is taking notice of me

For example:

- **Personal characteristics:** open, talkative, easy with people
- **Family roles – mother, father, sister, brother, grandparent:** mother, grandmother, wife
- **Hobbies, activities or interests:** cyclist, swimmer

2. When you think of yourself, what images come to mind?

Charity swims, Leeds Clarion.

"Spaghetti legs" nickname.

Cycling days – best friends, 'Tommie's Café'

Speaking again to 'Sandra' on 22.11.13, she added:

Brought up in a children's home

Do what I want to do

Outgoing, "Chatty Kathy"

3. What words describe you as a person?

'Fit as a butcher's dog' – loved dogs

Forward, take things as they come, help other people

4. Do you think people change when they move into a residential home?

Get used to it. It was not a big change for me, I grew up in a children's home so this is similar in some ways – and better.

5. What kinds of possessions are most important and what do they remind you of?

My den.

Resident 3

Date: 22.11.13 **Name:** 'Geoff' **Age:** NK

1. What do you think a sense of self or a sense of identity means?

For example:

- **Jobs you do or used to do:** engineer, building computers
- **Hobbies, activities or interests:** cycling, YHA

3. What words describe you as a person?

English, born in London

Lazy kind of person

4. What kinds of possessions are most important and what do they remind you of?

Armchair

Own bed

Family photos

Books, but don't read much now.

Appendix III: All documents sent to expert advisors

1.Questions for Expert Advisors: 'The Measure of Self'

General: overview of a measure of self.

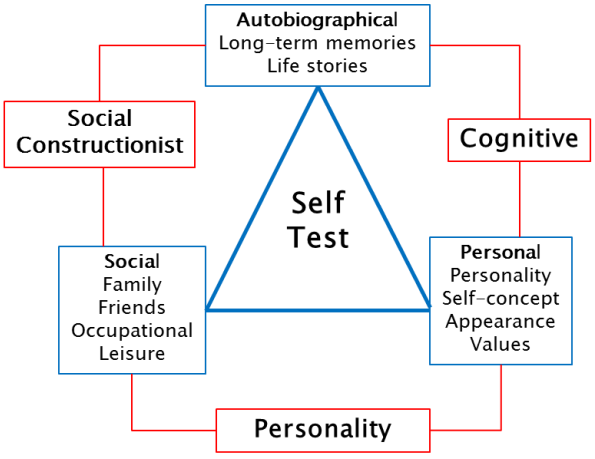
1. What do you think are the most important points to consider when developing an interview-based measure of self for people with dementia?

2. What are the main challenges?

3. Is it feasible for me to devise one measure that will cover differing levels of ability, or should there be two versions of the measure?

With reference to the conceptual model of self on which my measure will be built

I aim to ensure the measure includes autobiographical, personal and social aspects of self (as shown in the diagram below). This illustrates a conceptual model of self that I have developed and will use as a basis for developing the Measure of Self. The blue framework represents the multiple components of self that were identified in the literature review as being relevant for people with dementia. The red framework demonstrates theoretical approaches that provide evidence to link the components of self.



4. Is this diagram self-explanatory or do you have any queries about it? Are there any other aspects of self that you think should be included in the diagram?

The following questions relate to each measure. You need not look at every measure, just those that you are most familiar with.

5. What are your first thoughts about the measure and how applicable it is for people with dementia?

6. Does the measure relate to a 'holistic' view of self or specific aspects of self, with reference to the diagram above?

7. Could the test be adapted so that it does not have to rely as heavily on verbal communication, e.g. by use of pictorial or object cues when asking the questions, and pointing at words or images, or observation of gestures for responses?

8. Do you have any comments about the instructions for participants and/or the methods of analysis of their responses?

Details and Instructions for the 16 measures

1. The Self and Identity in Dementia Questionnaire (Cohen-Mansfield et al, 2000)
The Self and Identity in Dementia Questionnaire was developed to assess 4 domains of identity:

- Family relationships
- Work role/s
- Leisure activities
- Identity related to group membership, traits and achievements.

Research questions included:

- With which roles do people living with dementia identify?
- What is the strength of the sense of identity?
- What are the ways to elicit this identity?
- Which factors affect sense of identity?

Questionnaires were completed by people living with dementia ('participants'), and family members or carers. For the purpose of this study, only the questions that the people with dementia were asked will be considered.

Family roles
The participant is asked what family roles they have and how important they think each of them are to them personally.

Work roles
The participant is asked what jobs they used to have and how important these roles are/were to them personally.

Participants are asked to rate how important each role was/is to them personally on a 5-point scale:

1. Completely unimportant
2. Not very important
3. Neutral
4. Quite important
5. Very important

Leisure activities
The participant will be shown/read a list of activities and asked to say:

- Which activities he/she likes
- Which ones they wanted to do but were not able to do

The list of activities will include:

- Watching television
- Reading books
- Listening to music
- Spending time with friends
- Needlework or handicrafts
- Drawing or painting
- Dancing
- Hiking or walking in the countryside
- Telling stories
- Telling jokes
- Cooking
- Gardening
- Caring for pets
- Collecting things
- Travelling
- Watching films
- Playing or watching sport
- Religious activities
- Photography
- Politics

Personal attributes

The participant will be shown/read a list of attributes and asked which they are most proud of:

- Surviving to their current age
- Having a wide circle of friends
- Being proud of the success of a relative
- The place where they were born
- Previous occupations
- Their family history
- Their general knowledge
- Financial success
- Making a contribution to society
- Artistic skills
- Academic achievement
- Personal traits such as honesty, attractiveness, fitness, friendships.

Participants were also asked if there were specific personal articles that they desired to have with them, and how they like to be addressed by care staff.

Reference:

Cohen-Mansfield, J., Golander, H. and Arnheim, G. (2000) Self-identity in older persons suffering from dementia:preliminary results. *Social Science and Medicine*, 51, pp. 381-394.

2. The Social and Personal Identities Scale (SIPI, Nario-Redmond et al, 2004)

The Social and Personal Identities Scale is a measure of the differences in importance that people ascribe to their social and personal identities. Social identity is described as the tendency to categorize oneself in terms of one's group identifications, and personal identity is the tendency to describe oneself as an individual, distinct from in-group memberships.

The SIPI consists of a 16-item questionnaire:

Subscale and item	**Sequence in scale**
Social identity – SI	
The similarity I share with others in my group(s)	1
My family nationality or nationalities	3
The membership I have in various groups	5
The places where I have lived	7
My sense of belonging to my own racial group	9
My gender group	11
The colour of my skin	13
My being a citizen of my country	15
Personal Identity –PI	
My rebelliousness	2
My need to be completely distinct and unique from everyone else	4
My creativity	6
My sense of being different from others	8
My complete individuality	10
My boldness	12
My nonconformity	14
My sense of independence from others	16

Participants are asked to rate the importance of each statement ranging from 1 ("not at all important to who I am") to 9 ("extremely important to who I am"), plus an option of "not applicable to who I am". Scores can be totalled for each subscale.

Reference:

Nario-Redmond, M.R., Biernat, M., Eidelman, S., and Palenske, D.J. (2004) The Social and Personal Identities Scale: A Measure of the Differential Importance Ascribed to Social and Personal Self-Categorizations. *Self and Identity*, 3, pp.143-175.

3. The Sense of Belonging Scale (Hoffman et al, 2002-3)

The sense of belonging scale was originally developed for first year college students. Sense of belonging can be defined as " the experience of personal involvement in a system or environment so that persons feel themselves to be an integral part of that system or environment".

The scale consists of 50 items, but many of these are specifically related to college environments and activities. Participants were given a written questionnaire and were asked to read each item carefully and asked to rate their agreement with each statement by choosing from 5 responses:

1. Completely true
2. Mostly true
3. Equally true and untrue
4. Mostly untrue
5. Completely untrue

The following items have been selected that could be applicable for people living with dementia:

1. I feel comfortable talking in my group.
2. I like knowing other people in my group.
3. I have made new friends by joining groups.
4. I feel alone when I am in my group.
5. I rarely talk to other people in my group.
6. I ask people in my group to help me if I have a problem.
7. I say hello to people I recognise from my group when I see them outside of the group.
8. It is easy for me to get in touch with someone from my group if I have a problem.
9. People I know from my group invite me to do other things with them.
10. I do other activities with people from my group.

Reference:

Hoffman, M., Richmond, J. et al (2002-2003). Investigating "Sense of Belonging" in First year College Students. *Journal of College Student Retention*, 4(3), pp.227-256.

4. The Adjective Check List/Creative Personality Scale (Gough, 1979)

The Creative Personality Scale consists of 30 positive and negative adjectives. Participants covered a wide range of ages and kinds of work. The measure was designed to identify creative talent within an individual so the positive and negative distinctions relate to aiding or hindering creativity. Participants are asked to rate how well the adjectives describe them using a 4-point scale:

1. Does not describe me at all
2. Describes me a bit
3. Describes me quite a lot
4. Describes me absolutely

Positive items:

- Capable
- Clever
- Confident
- Egotistical
- Humorous
- Individualistic
- Informal
- Insightful
- Intelligent
- Inventive
- Original
- Reflective
- Resourceful
- Self-confident

- Sexy
- Snobbish
- Unconventional
- Wide interests

Negative items:

- Affected
- Cautious
- Commonplace
- Conservative
- Conventional
- Dissatisfied
- Honest
- Mannerly
- Narrow interests
- Sincere
- Submissive
- Suspicious

Reference:

Gough, H.G. (1979). A creative personality scale for the Adjective Checklist. Journal of Personality and Social Psychology, 37(8), pp.1398-1405.

5. The Life Orientation Test (LOT, Scheier & Carver, 1985)

The Life Orientation Test is a scale measuring dispositional optimism, defined in terms of generalised outcome expectances.

Instructions

Participants are asked "*Please answer the following questions about yourself by indicating the extent of your agreement using the following scale:*

- *0 = strongly disagree*
- *1= disagree*
- *2= neutral*
- *3= agree*
- *4= strongly agree*

Be as honest as you can throughout, and try not to let your responses of one question influence your responses to other questions. There are no right or wrong answers."

1. In uncertain times I usually expect the best.

2. It's easy for me to relax.

3. If something can go wrong for me it will.

4. I always look on the bright side of things.

5. I'm always optimistic about my future.

6. I enjoy my friends a lot.

7. It's important for me to keep busy.

8. I hardly ever expect things to go my way

9. Things never work out the way I want them to.

10. I don't get upset too easily.

11. I'm a believer in the idea that "every cloud has a silver lining".

12. I rarely count on good things happening to me.

Scoring

1. Reverse code items 3, 8, 9, and 12.

2. Sum items 1, 3, 4, 5, 8, 9, 11, and 12.

Note: Items 2, 6, 7 and 10 are filler items only. They are not scored as part of the scale.

Reference:

Scheier, M.F. and Carver, C.S. (1985) Optimism, coping, and health: Assessment and implications of generalized outcome expectations. *Health Psychology*, 5, pp.219-247

6. The Rosenberg Self-Esteem Scale (Rosenberg, 1965)

The Rosenberg Self-Esteem Scale consists of 10 items that are scored on a 4-point scale:

- Strongly agree
- Agree
- Disagree
- Strongly agree

Instructions

Below is a list of statements dealing with your general feelings about yourself. If you strongly agree, circle SA. If you agree with the statement, circle A. If you disagree, circle D. If you strongly disagree, circle SD.

1.	On the whole, I am satisfied with myself.	SA	A	D	SD
2.*	At times, I think I am no good at al.	SA	A	D	SD
3.	I feel that I have a number of good qualities.	SA	A	D	SD
4.	I am able to do things as well as most other people.	SA	A	D	SD
5.*	I feel I do not have much to be proud of.	SA	A	D	SD
6.*	I certainly feel useless at times.	SA	A	D	SD
7.	I feel that I'm a person of worth, at least on an equal Plane with others.	SA	A	D	SD
8.*	I wish I could have more respect for myself.	SA	A	D	SD
9.*	All in all, I am inclined to feel that I am a failure.	SA	A	D	SD
10.	I take a positive attitude towards myself.	SA	A	D	SD

Scoring

SA=3, A=2, D=1, SD=0. Items with an * are reversed scored, i.e. SA=0, A=1, D=2, SD=3. The higher the total score, the higher the self-esteem.

Reference:

Rosenberg, M. (1965). *Society and adolescent self-image*. Princeton, NJ: Princeton University press.

7. The Autobiographical Memory Interview (AMI, Kopelman et al 1989)

The AMI provides a useful research tool for investigating retrograde amnesia. Patients who may be very similar on standard memory tests can differ markedly in their autobiographical memory performance.

The test assesses a person's recall of **facts** from their own past life and also assesses their recall of **specific incidents** in their earlier life.

Both types of memory are assessed across three broad time bands:

- Childhood
- Early adult life
- Recent facts/incidents

This allows a measurement of the pattern of autobiographical memory deficit, and the detection of any temporal gradient in retrograde amnesia.

The AMI provides an assessment of a person's personal remote memory, in contrast to other tests which probe memory for public events and personalities. As such, the test is not dependent on the level of a person's habitual interest in current affairs and news events. Furthermore, it does not require regular updating in the same way as remote memory tests based on public events.

Background

Retrograde amnesia often leads to an impairment of autobiographical memory, the capacity to recollect the facts and incidents of one's earlier life. Although not measured by standard memory tests, it is valuable to assess autobiographical memory:

- To understand the nature of the memory deficit observed
- To provide an individual focus for subsequent treatment, such as reminiscence therapy.

The AMI consists of 2 components:

- The Autobiographical Incidents schedule
- The Personal Semantic Memory Schedule

The Autobiographical Incidents Schedule

Participants are required to produce a memory of a specific incident from their past, relating to each of the items specified in the table below. They are encouraged to produce a specific memory and to state when and where it happened (e.g. " Being knocked of a bicycle by a milk van on Beech Avenue aged 14…") rather than a general memory (e.g. "We used to play football at school, which I enjoyed"). If a participant fails to produce any memory, he or she is prompted using cues indicated in the table.

A handwritten record of each memory produced is written down and scored using a 0 to 3 point rating scale (Baddeley & Wilson, 1987). Scoring is in terms of the descriptive richness of the account of an incident, and its specificity in time and place:

Episodicity Rating Scale (the participant cannot use the same memory twice, only one score)

Score 3: Episodic memory, specific in time and place

e.g.: a 78-year-old woman recalling her first job:

"*They gave us a day out in London in one of the hotels – we had a reception. They took us up in cars from Peckham about 6.00 to a big hotel in central London (I don't know the name). A lovely car. There was a dinner and a big speech. I think it was to celebrate their centenary. Mr. Heinz came over from America to make a speech….I was 18 at the time."*

Score 2: Personal but non-specific event, or a specific event but time and place not recalled
e.g.: A 67-year-old man with multi-infarct dementia recalling his first job at an Admiralty laboratory:

"*I played a lot of cricket – kept wicket for the lab team. The ground was in Bushey Park. I scored a century one year. We used to travel to Barnes and places on the Thames. I scored a lot of runs one year. I can't remember anything more about it."*

Score 1: Vague personal memory
e.g.: a 29-year-old man with carbon monoxide poisoning recalling his first job as a customs officer:

"All paperwork – very boring. The first day I checked where I was living. John Brown was a jovial fellow. Interesting fellow. Would laugh and joke – wouldn't worry if something went wrong."

Score 0: No response or a response based on semantic memory
e.g.: a 74-year-old woman with vascular dementia recalling her time at a shorthand typing college:

"It was very well run. I can't remember any incidents or friends. Perhaps the war was on."

Time Period	Incident to be recalled	Suggested prompts
1. Childhood (9 points max)	1. Before school 2. At primary school (5 to 11 years) 3. At secondary school (11 to 16/18 years)	→ First memory → Involving brother or sister → Involving a friend → Involving a teacher
2. Early adult life (9 points max)	1. First job or starting college/university 2. Wedding: own or other during 20s 3. Meeting someone during 20s	→ First day at work/college/university → Episode with friend/girlfriend/boyfriend → The guests → At reception
3. Recent events (9 points max)	1. A relative or visitor in the last year 2. An event in this building/ place where being interviewed 3. A journey in the last year	→ e.g. an interview → On holiday or at work → Visit by/to a relative → News about a relative → Involving other people/clients/doctors etc. → Place visited → Someone met

Personal Semantic Memory Schedule: participants are required to answer questions regarding their knowledge of facts about their past.

Time period (and score)	Item	Examples of/ individual questions
1. Background information (23 points)	1. Parents/guardians 2. Brothers/sisters 3. Self	→ Names, date of birth, where born, occupation, address, or when and where born. → As above → Date of birth, where born → Address where living → Names of friends
2. Childhood (21 points)	1. Before school 2. First school (infants or primary) 3. Secondary school (at age 13)	→ Name of school, where, age at starting → Own address → Names of friends/teachers
3. Early Adult Life (21 points)	1. First job/or college/or university 2. Wedding – own or other during 20s 3. Children – own/niece or nephew/close friends'	→ Name of firm, college/qualifications → Own address → Names of boss/colleagues → Whose/where/when → Address before/after → Names of best man/bridesmaids → Names of two children/ when and where born
4. Recent information (21 points)	1. Hospital or other institution 2. Christmas and visits 3. Holidays or other journeys in last year (or within last 5 years)	→ Current/name/place/when first came/names of staff/or clients/ or residents → Current address → When and where last in hospital → Where living then → Where last Christmas spent → Who with → Names of visitors or relatives seen in the last year → When/where/who with

8. The Autobiographical Memory Interview – Extended (Naylor & Clare, 2008, Subramaniam et al, 2014)

Naylor and Clare noted that the AMI does not assess the period between early adulthood and recent life and that this may represent a possible limitation when participants are in an older age range. Therefore, a "middle to late adulthood" section was added, developed specifically for use with people who have a diagnosis of dementia. It was acknowledged that the additional section was not standardised and may differ from the standard AMI in level of difficulty, however, it was considered to be of interest by exploring the accessibility of autobiographical information from the mid-life period.

References:

Kopelman, M.D., Wilson, B., and Baddeley, A. (1990) *The Autobiographical Memory Interview*. Suffolk, UK: Thames Valley Test Company.

Addis, D. R. and Tippett, L. J. (2004) Memory of myself: Autobiographical memory and identity in Alzheimer's disease. *Memory*, 12 (1), pp.56-74.

Naylor, E., and Clare, L. (2008) Awareness of memory functioning, autobiographical memory and identity in early-stage dementia. *Neuropsychological Rehabilitation*, 18 (5/6), pp.590-606.

Subramaniam, P., Woods, B. and Whitaker, C. (2014) Life review and life story books for people with mild to moderate dementia: a randomised controlled trial. *Aging and Mental Health*, 18(3), pp.363-375.

9. The Autobiographical Interview (Levine et al, 2002)

The Autobiographical Interview is a method of assessing autobiographical memory from within a single narrative using text-based analysis of transcribed memories. It provides a wealth of information concerning elements of naturalistic autobiographical memory. Most importantly, the scoring method separates episodic details (i.e. description of the event, sensory or mental state details specific to the event) from non-episodic details (i.e. semantic or factual statements, or other details not specific to the event). These are classed as internal and external details.

Procedure

Participants are asked to talk about one life event from five life periods:

- Early childhood (up to age 11 years)
- Adolescent-teenage years (11 to 17 years)
- Early adulthood (18 to 35 years)
- Middle age (35 to 55 years)
- Previous year

Instructions read by researcher:

" I am going to ask you to tell me about an event from each of these time periods in your life (list of life periods is provided). You can choose any events you wish."

"I will ask you to describe the events then I will ask you some questions about them. The event must be something you were personally involved in, and you must have a recollection of being personally involved. They must be events from a specific time and place. For example, playing football at school would not be enough, but an event involving a specific football game would be good. I want you to provide as much detail as you can about the event."

"Do not pick events that you have heard about from other people. I am not interested so much in which events you choose, but rather how you describe them. So do not feel pressured to pick any particular event."

"I want you to know that I will be asking you to give some details for these events later, so be sure to only choose events that you feel comfortable discussing in detail."

Conditions of Retrieval Support
Retrieval support is provided as three conditions: recall, general probe, and specific probe:

Recall
In this condition, participants simply talk about the event as it comes to mind without any interruption from the researcher, continuing until they have reached a natural ending point.

General probe
After an event is recalled, general probes are used to clarify instructions and to encourage greater recall of more details, e.g. if a participant cannot recall a specific event: *"Can you tell me a specific instance of…?*" or if a recollection is very brief: "*Is that everything you can say about it? I would like to know all of the details that come to mind".*

If general probing does not elicit a specific event, the participant is given the option of selecting a different event that is more likely to result in successful recall.

Specific probe
This condition consists of a structured interview designed to elicit additional details that are not spontaneously recalled. Questions are organised into 6 categories (see Table 1)

Scoring
Each memory is segmented into informational bits or details. A 'detail' is a unique occurrence, observation or thought, typically expressed as a grammatical clause, e.g. "*I dropped my sandwich*".

Additional 'information' in the clause is scored separately, e.g. "*I dropped my sandwich in Whitby last Wednesday*" contains 3 details: an event (dropping the sandwich); a location (Whitby) and a time (last Wednesday).

There are two groups of details: internal and external:

Internal details pertain directly to the main event such as time and place which is taken to represent episodic re-experiencing. They are separated into five mutually exclusive categories (see Table 1:

External details are mainly semantic (factual information or extended events that do not include recollection of a specific time and place). Repetitions were also classed as external, and details that pertain to specific autobiographical events other than the main defined event (see Table 1).

Rating Assignment

Ratings are assigned for episodic richness as described in Table 1. Time, place, perception, and emotion/thoughts are rated on a scale of 0 to 3 according to the following guidelines:

3 points: A rich, highly specific, evocative, and/or vivid description that appears to emerge from a feeling of re-experiencing.

2 points: A detailed description that falls short of 3 points in the degree of richness.

1 point: A description that is limited to general, nonspecific information but is still episodic in nature.

0 points: No mention of information pertaining to the specified category, or a response that is based on semantic knowledge rather than episodic memory.

Table 1: Description of Scoring Categories

Category	Description
Internal	
Event	Happenings, individuals present, weather conditions, physical/emotional actions, or reactions to others.
Time	Year, season, month, day of week, time of day.
Place	Localization of an event including the city/town, street, building, room or part of room.
Perceptual	Auditory, olfactory, tactile, taste, visual and visual details, body position, duration.
Thought/Emotion	Emotional state, thoughts, implications
External	
Event	Specific details from other incidents external to the main event recalled.
Semantic	General knowledge for facts, ongoing events, extended states of being.
Repetition	Unsolicited repetition of details.
Other	Metacognitive statements, editorializing.

Reference:
Levine, B., Svoboda, E., Hay, J., Wincour, G. and Moscovitch, M. (2002) Aging and Autobiographical memory: Dissociating Episodic from Semantic Retrieval. *Psychology and Aging*, 17(4), pp.677-689.

10. Twenty Statements Test (Kuhn & McPartland, 1954)

The 20 Statements Test is a simple and commonly used technique for initial, rough assessment of an individual's sense of self or identity. For the technique to have any validity you will need to complete the following section **before** reading the "Scoring Instructions" on the next page.

PLEASE COMPLETE THE FOLLOWING SENTENCE USING A DIFFERENT WORD OR PHRASE EACH TIME THAT YOU BELIEVE IS TRUE ABOUT YOURSELF.

I am:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____

Scoring Instructions

The simplest way to score is to categorize each of the statements as:

External: locates a person within society by describing a social role, e.g. mother, father, son, daughter, brother, sister, grandparent, marathon runner, jazz fan, etc.

Internal: describes an interior quality or trait, e.g. intrinsic characteristics such as shy, ambitious, happy, stable, confused, contented, curious, etc.

Put **E** or **I** beside each statement. Total the number in each category:

External descriptions: _____

Internal descriptions: _____

Total no. of descriptions: _____

Addis & Tippet (2004) adapted the Twenty Statements Test to make it suitable for people with Alzheimer's disease. Instead of a written format it was administered verbally, and the instructions were adapted for verbal administration. Prompts suggesting possible types of response (e.g. characteristics, roles, abilities) were added to the instructions. Responses were recorded verbatim by the researcher until 20 were recorded.

Rathbone et al (2008) varied the Twenty Statements Test by asking their participants to write down ten statements that they felt "defined their identity". Following this, participants were asked to select three of the ten statements that were "most personally significant to [their] sense of identity" for which they could recall memories. Each of the three statements was used to generate 10 memories, for example, "*I am a wife*" generated recall of "*my wedding day*". Participants also reported the age at which they felt each of the three statements became a "defining part of their identity". The purpose of this study was to examine the distribution of autobiographical memories around the times of identity formation.

References:

Addis, D. R. and Tippett, L. J. (2004) Memory of myself: Autobiographical memory and identity in Alzheimer's disease. *Memory*, 12 (1), pp.56-74.

Kuhn, M.H. and McPartland, T.S. (1954). An Empirical Investigation of Self Attitudes. American Sociologicaln Review, 19(1), pp.68-76

Rathbone, C.J., Moulin, C.J.A., and Conway, M.A. (2008) Self-centred Memories: The Reminiscence Bump and The Self. *Memory and Cognition*, 36(8), pp. 1403-1414.

11. The Oral I-AM (Identity-Alzheimer-Moderate) Test (Eustache et al, 2013)

The I-AM Test is an adaptation of the Twenty Statements Test; owing to the cognitive difficulties of people with Alzheimer's disease, a modified version was designed in which participants are asked to complete 10 "I am…." statements orally. Participants are encouraged to describe who they are and their own perceptions of themselves without having to worry about the importance of their responses. There was no time limit, but in practice the test took less than 20 minutes. The researcher writes down the participants' answers and, if necessary, encourages them to continue in as neutral a way as possible.

Scoring

Scoring depends on the number of statements provided, and the number of different categories of responses as described below (see also Table 1):

Idiocentric responses reflect an independent type of self-concept, i.e. statements refer to personal qualities, attitudes and states that are not related to other people, such as physical features, personality traits, and preferences.

Small group and **large group** responses reflect interdependent self-concepts.

Allocentric responses are socially oriented because they involve interdependence and other people's viewpoints, also subdivided into personality traits and preferences.

Scoring also included the emotional valence associated with responses, if appropriate.

Table 1: Coding scheme for the I-AM Test

Categories	Subcategories	Emotional valence	Example
Idiocentric	Physical	Positive, negative or	I am big-boned
Idiocentric	feature	neutral	I am an enthusiastic person
Idiocentric	Personality	Positive, negative or	I am a person who likes to travel
	trait	neutral	
Small	Preference	n/a	I am a grandfather
group			
		n/a	I am a pensioner
Large			
group		n/a	I am a sociable person
			I am a person who likes to be
Allocentric	Personality	Positive, negative or	needed
Allocentric	trait	neutral	
	Preference	n/a	

The following scores are calculated:

- The overall number of statements generated.
- The number of responses belonging to each category or subcategory
- Their emotional valence
- The number of different categories (max 4)
- The number of subcategories (max 7)
- The number of sentences in which a person clearly stated they no longer knew who they were.
- The number of sentences that were obviously erroneous at the time of testing (e.g. "I am a student"), but which could have been true in the past.

Reference:

Eustache, M-L., Laisney, M., Juskenaite, A., Letortu, O., Patel, H.,Estache, F., Desgranges, B. (2013) Sense of identity in advanced Alzheimer's dementia: A cognitive dissociation between sameness and selfhood? *Consciousness and Cognition*, 22, pp1456-1467.

12. The 3-I Test (Duval et al, 2012)

The 3-I test was inspired by the Twenty Statements Test and adapted and extended to obtain both 'structural' (identity trait self-knowledge and autobiographical memory) and 'functional' (self-consciousness and self-projection) measures related to self-representations in the past, present and future.

The self-assessment measure consists of two parts:

1. Emphasised abstracted semantic self-representations (trait self-knowledge)
2. Explored episodes of personal events related to the abstracted semantic self-representations.

Part 1

Participants are asked to provide five written statements, each beginning with "I am…", then "I was…." And "I will be…" in answer to the question "Who am I?"

Detailed instructions were given to the participants:

1. They were first asked to define and describe their personal identity (through general self-representations, self-perceptions or self-images) by completing five "I am…" statements, in the order that they occurred to them, without worrying about logic or importance. No time limit was given, but in practice this part lasted about 10 minutes.
2. Participants next completed five "I was…" sentences to describe their past identity, or the way they perceived themselves to be in the past.
3. Participants completed five "I will be…" sentences outlining their future identity.

These periods were described as present, past and future. For each period, participants are asked to indicate the average age to which their descriptions referred on a scale ranging from birth to 100 years of age.

This part yields two theoretical scores of conceptual self:

1. Strength of self-concept related to *structural self* (i.e. identity and trait self-knowledge) is calculated according to the number of sentences supplied for each period.
2. Temporal distance of self-projection related to *functional self* measured in terms of the distance between the participant's real age and the age to which his/her descriptions referred for each time period. This supplies information about the process of mental time travel.

Part 2

Participants are asked to choose two sentences from each time period (present, past and future) which they consider to be most representative of their identity. They are next asked to evoke in detail a specific related experience which helps to explain why the selected characteristic is an integral part of their identity.

Each memory is scored using an analytical semantic/episodic scoring procedure, taking into account aspects such as specificity according to uniqueness, spatial and temporal contexts (place, time and date) and the presence of phenomenological (images, thoughts etc.) and emotional details.

Reference:

Duval, C., Desgranges, B., de La Sayette, V., Belliard, S., Eustache, F., and Piolino, P. (2012) What happens to personal identity when semantic knowledge degrades? A study of the self and autobiographical memory in semantic dementia. *Neuropsychologia*, 50, pp.254-265.

13. The Tennessee Self-Concept Scale-II (TSCS-II, Fitts & Warren, 1965)

The Tennessee Self-Concept Scale is one of the most widely used measures of self-concept in children, adolescents and adults. It enables easy scoring procedures and guidance in interpreting scores to help guide therapeutic interventions. The test provides 4 sets of scores, giving a total of 15 sub-scores:

Self-Concept Scores:

- Physical
- Moral

- Personal
- Family
- Social
- Academic/work

Summary Scores:

- Total self-concept
- Conflict

Supplementary Scores:

- Identity
- Satisfaction
- Behaviour

Validity Scores:

- Inconsistent responding
- Self-criticism
- Faking good
- Response distribution

The complete TSCS-II consists of 82 descriptive statements which are rated for self-descriptiveness on a 5-point true-false scale:

1. Always false
2. Mostly false
3. Partly false and partly true
4. Mostly true
5. Always true

Addis & Tippet (2004) used the 21-item identity component only, modifying the administration for people with Alzheimer's disease. Instead of a written questionnaire each item was read aloud and presented on a laminated card consisting of the statement and a 5-point true-false scale.

The 21 'Identity' items are:

1. I have a healthy body
2. I like to appear neat and attractive
3. I am full of pain and suffering
4. I am an untidy person
5. I am not a healthy person
6. I am a well-mannered person
7. I am an honest person
8. I am a bad person
9. I am a weak-willed person
10. I am a cheerful person
11. I have high self-control
12. I am a calm person and easy to befriend
13. I am not important
14. I can no longer think straight
15. I am not loved by my family
16. I think my family do not trust me.
17. I am a friendly person
18. I feel angry towards everybody
19. I am not interested in what others are doing
20. I find it difficult to develop closeness with others
21. My friends have no confidence in me

For each statement, a higher score indicates a more positive identity. It is also possible to determine five identity sub-scores: personal, family, social, moral and physical.

The number of vague responses scoring 3 ("partly false and partly true"), and the number of definite responses scoring 1 ("always false") and 5 ("always true") were used as measures of the quality of identity.

References:

Addis, D. R. and Tippett, L. J. (2004) Memory of myself: Autobiographical memory and identity in Alzheimer's disease. *Memory*, 12 (1), pp.56-74.

Fitts, W.H. (1965) *Tennessee Self-Concept Scale*. Nashville, TN: Counselor Recording and Tests.

14. The IMAGE Test (Eustache et al, 2013)

The IMAGE Test was adapted for use with people with Alzheimer's disease, including the advanced stage, from the TSCS-II, and other measures of self-consciousness and self-representation. The structure of the IMAGE Test is based on the TSCS-II, and measures three components of self-concept (identity, behaviour, and self-satisfaction) in seven domains (moral-ethical, social, personal, physical, family, cognition and emotion).

The IMAGE Test is composed of 24 descriptive statements, of which 21 refer to the three self-concept components (each consisting of 7 statements), and three statements relating to private self-consciousness, as described in Table 1 below:

Table 1: IMAGE Test Statements

Components + Statements	Domain	Direction
Identity		
I am an honest person	Moral-ethical	Positive
I am sociable	Social	Positive
I am naturally cheerful	Personal	Positive
I am physically quite attractive	Physical	Positive
Family is important to me	Family	Positive
I am quite serious-minded	Cognition	Positive
I am rather a sad person	Emotion	Negative
Behaviour		
I sometimes act immorally	Moral-ethical	Negative
I find it hard to talk to people I don't know	Social	Negative
I lack self-confidence	Personal	Negative
I don't care about my appearance	Physical	Negative
I rarely quarrel with my family	Family	Positive
I have difficulty learning things	Cognition	Negative
I don't often get angry	Emotion	Positive
Self-satisfaction		
I tell lies far too often	Moral-ethical	Negative
I ought to be more friendly to people	Social	Negative
I am happy with who I am	Personal	Positive
I am satisfied with the way I look	Physical	Positive
I ask too much of the people around me	Family	Negative

I am satisfied with my intellectual abilities I live too much in the past Private self-consciousness I don't often think about who I am I generally pay attention to what I feel I find it hard to detect my mood swings	Cognition Emotion	Positive Negative Negative Positive Negative

Half of the descriptive statements are positive, and half are negative. The statements are worded so that they can be understood easily by people with Alzheimer's disease.

The statements are presented by the researcher in the form of a question to the participant, asking him/her to reply if it is true or false. The participant is then asked to say if the statement was totally false/true or only partly false/true. Instructions were repeated if necessary.

The researcher recorded the participants' responses on a 4-point scale:

1. Totally false
2. Partly false
3. Partly true
4. Totally true

The total score (sum of all items, maximum 96) reflects the participant's overall sense of identity and level of self-esteem, indicating a generally positive or negative self-view. Sub-scores can also be calculated for each of the 4 sub-components:

1. Identity: (maximum 28) reflects how the participants describe who they are.
2. Behavioural: (maximum 28) reflects how participants describe their actions.
3. Self-satisfaction: (maximum 28) reflects how participants feel content with themselves
4. Private self-consciousness: (maximum 12) reflects how participants observe and analyses themselves, especially aspects that are personal and not easily accessible to the scrutiny of others, such as a person's own feelings.

It is also possible to report the number of definite responses for each of the 4 sub-components; 1 (totally false) and 4 (totally true), and the total number of definite responses.

Reference:

Eustache, M-L., Laisney, M., Juskenaite, A., Letortu, O., Patel, H.,Estache, F., Desgranges, B. (2013) Sense of identity in advanced Alzheimer's dementia: A cognitive dissociation between sameness and selfhood? *Consciousness and Cognition*, 22, pp1456-1467.

15. The Questionnaire of Self-Representation (QSR, Duval et al, 2012, Eustache et al, 2013)

The Questionnaire of Self Representation incorporates elements of several commonly used measures of self-concept, including the TSCS-II, consisting of 50 positive and negative descriptive statements. The statements are read aloud to participants who are asked to indicate to the researcher how well each statement describes them on a 4-point scale printed on a separate sheet:

1. Does not describe me at all
2. Describes me a little
3. Describes me well
4. Describes me absolutely

Task instructions were repeated and two rewordings of each item were provided if necessary. If the participant's understanding of items remained impaired after 3 items or more, they were withdrawn from the task. The following list presents some of the statements:

1. I think about myself a lot

2. I day dream a lot

3. I never scrutinize myself

4. I am generally attentive to my inner feelings

5. I'm alert to changes in my mood

6. I'm self-conscious about the way I look

7. One of the last things I do before leaving my house is to look in the mirror

8. I get embarrassed very easily

9. I am a healthy person

10. I like to look neat and tidy

11. I am an untidy person

12. I like the way I am now

13. I feel happy most of the time

14. I was not good at games or sports

15. I have trouble sleeping

16. I am a well-mannered person

17. I am a calm person

18. I often change my mind

19. I am a friendly person

20. I like to spend time with other people

21. Sometimes I get angry

22. I prefer to win rather than lose a game.

The stability of self-knowledge is measured as a 'certainty of self-concept score' by totalling the number of definite responses (scoring 1 and 4) which indicated clear-cut self-representations. Scores of 2 and 3 are regarded as 'vague' responses. Self-esteem (functional self) is calculated from the positive and negative valence of each statement.

References:

Duval, C., Desgranges, B., de La Sayette, V., Belliard, S., Eustache, F., and Piolino, P. (2012) What happens to personal identity when semantic knowledge degrades? A study of the self and autobiographical memory in semantic dementia. *Neuropsychologia*, 50, pp.254-265.

Eustache, M-L., Laisney, M., Juskenaite, A., Letortu, O., Patel, H.,Estache, F., Desgranges, B. (2013) Sense of identity in advanced Alzheimer's dementia: A cognitive dissociation between sameness and selfhood? *Consciousness and Cognition*, 22, pp1456-1467.

Extra information for Questionnaire of Self Representation

Used for people with Semantic dementia:

People with SD generated the same number of clear-cut responses as controls, indicating certainty about the way they saw themselves; they seemed to have consistent and stable self-concepts of traits and of self-esteem, and displayed positive self-esteem. In spite of general semantic impairment, and deficits in personal semanticised events, participants successfully distinguished between abstract and conceptual self-concept to describe themselves. One possible explanation is that the organization of trait self-knowledge is better preserved than other areas of semantic knowledge. Given that there was no reduction in strength and certainty of self-concept, SD participants' identity seemed preserved, they knew who they were and their self-image was not frozen in the present.

16. The Physical Self-Concept Scale for Older Adults (PSCS-OA, Hsu & Lu, 2013)

Physical self-concept plays a central role in older adults' physical and mental health and psychological well-being. The Physical Self-Concept Scale is a measure of physical self-concept in older adults.

Instructions
Each participant is asked to indicate his/her level of agreement with each of the statements on a 4-point scale:

1. Always false
2. Mostly false
3. Mostly true
4. Always true

The PSCS-OA consists of the following items:
1. I am satisfied with my weight.
2. My waist is too large.
3. I can fit into whatever I want to wear.
4. Bending down to pick things up is easy for me.
5. My body is stiff.
6. I can squat down and stand up easily.
7. My appearance looks younger than most of my friends.
8. I have an older looking face.
9. I have many characteristics of old age, such as wrinkles and grey hair.
10. I can walk a long way without stopping.
11. I am capable of doing most physical activities.
12. I can be physically active for a long time without getting tired.
13. I get ill a lot.
14. I think I go to the doctor more often than most people my age do.
15. When I get ill, it takes me a long time to recover my health.
16. I can live my life independently.
17. I can clean the house without help.
18. No matter how long the distance is, I can go wherever I like independently.

Reference:

Hsu, Y-W. and Lu, F. J-H. (2013) The Development and validation of the Physical Self-concept Scale for Older Adults. *Educational Gerontology*, 39(7), pp.501-513.

Appendix IV: Summaries of Expert Advisors' Responses to General Questions

Question	EA1	EA2	EA3
1. What do you think are the most important points to consider when developing an interview-based measure of self for people with dementia?	1. Self is multifaceted – there are many elements to how self is constructed e.g. Klein's model of 7-aspects of self. 2. How can different aspects be tested to cover all bases? 3. What is the tool trying to achieve? One test that looks at one aspect very well or one that taps all aspects? 4. Is this possible for a short task that non-experts can deliver?	1. There cannot be only one interview. 2. Each interview should take no longer than 1 hour. 3. Establish trust and rapport with the interviewee. 4. A person may tell you different things 'freeform' than they would by choosing pre-determined answers (e.g. rating scale)	1. Tension between quantitative and qualitative methods. 2. Tension between discourses of self that are tied to particular disciplines. 3. Consider philosophical views of self – e.g. Merleau-Ponty and Bourdieu re. habitus. 4. Ensure theoretical background of perspectives we are drawing on is explained. This has implications for how what observed is translated into a measurement. 5. Will require quite extensive note-taking in terms of understanding why self is expressed in the way that it was, or why it wasn't? 6. Self is enormous and complex and multidimensional and multifaceted. Can one measure capture it all?
2. What are the main challenges?	1. Conflict between having something that taps into everything in a sophisticated way and on the other	1. You need to know not **what** a person feels but **why** they feel as they do, which can take a long time, over	1. How can an objective measure capture all the different aspects of self?

	hand, something that can be delivered briefly. 2. To have maximum impact, measure needs to be easy to deliver without needing a lot of props that would be expensive, unwieldy and difficult. 3. As a first approach, choose simpler option. No point in developing a complicated tool that never gets used. 4. Focus on something streamlined rather than trying to do everything.	several interviews.	2. How can expressions of self be observed? E.g. food preferences. 3. Gestural communication used to compensate for things that can't be expressed verbally. 4. How to approach measurement when measures are decontextualized? 5. Behaviour can be seen as symptomatic of dementia, but can be shown to have meaning in particular contexts. 6. How to learn about previous occupations etc. without too much investigation. 7. Cueing memories would require quite an elaborate set up. 8. Music may be sufficient - can facilitate self-expression, even after the music stops. But does the music become an intervention rather than just a cue? 9. The way the cue works may affect how the person completes the measure – so how can it be standardised? What does it mean if the cue doesn't work?
4. Is the diagram (of self) self-explanatory or do you have any	1. Add behaviours? Can they be added feasibly? Is it important? Is it part of	1. 'Personality' – this is not independent of other people. A	Consider the different kinds of self-expression that I've documented

queries? Can you think of anything to add to it?	someone's autobiography? 2. How would all aspects of diagram be covered by a simple task that lots of people could give? 3. Diagram covers a lot of what can be described as self-knowledge, c.f. James's 'me' – i.e. how people can describe 'me': this is part of who I am. 4. What about 'I'? This is much harder to measure – i.e. distinguish between self-knowledge and self-consciousness – not trying to measure the whole self seems sensible. 5. Add thinking about the future (ref. Klein)? – more work being done about this now.	person can be outgoing with some, and introverted with others or in particular situations. 2. 'Self-concept' may also vary with social situations. Do people with dementia show personality change, or is it that they now say things that they used to think, but didn't say? 3. Re. 'autobiography' – how you get at life story matters. Asking people to recall on command may be more difficult than asking them to look at photos. Having a conversation that goes here and there triggers information that may not be elicited by a command. 4. Allow conversations to be 'freeform', then complete 'tick boxes'. 5. Responses may not be in response to a particular question, but come from somewhere else, or a previous question. 6. Self-constructs are not separate – are all inter-connected. You can connect personality with family, friends, occupation etc.	across my scholarship: 1. Self-awareness 2. Religious practices – but would require the whole orchestration of the event to elicit complete memories and selfhood. 3. Creativity – singing, dancing, painting – triggered by physical objects put into a person's hands more effective than questions. 4. Engagement with music can be very powerful. 5. Behaviours that express previous vocations/occupations. 6. Etiquette. 7. Relationships - consider movement away from person-centred care to relational care.

Appendix V: Sample Transcripts of Interviews with Expert Advisors

Expert Advisor Interview – 'EA1'/22/7/15 (face to face)

RB**:** I'll just work through these general questions first. What do you think are the most important points to consider when developing an interview-based measure of self for people with dementia?

CR: Okay, my background is I'm trying to measure self a little bit but I am not sure about answering questions about dementia, so obviously everything I say about dementia is based on the fact that I have only done one study with dementia. In terms of the self, and I can see that you know this from the documents you have sent me, I think that one of the most important things is that the self is multi-faceted, so the self isn't just one thing, and there are lots of different elements to how people might develop and describe and construct a sense of self. So that multifaceted aspect is one of the most important things. And as I was reading the materials you sent me, I thought of Stanley Klein's work (I think it's from 2012) – he had the framework of seven…

RB: I'm familiar with that, yes.

CR: I think that comes through. How can you test these different aspects in a way that means you are covering all the bases; whether you have to cover all the bases? So these are questions that the answer to which would depend on what you are trying to achieve with your tool. Whether you want to have something that just looks at one thing very well, or whether you need to have something that taps into all the different aspects of the self, and whether that's even possible in a short task that non-experts can deliver. I don't have the answer to those questions but I know that they are important questions.

RB: Well they are the most important points if you think they are the most important points, so that's all very useful thank you.

CR: Okay, that's alright. Oh there was one more thing which I was wondering and I wanted to see what you thought about this, and I know this; some perspectives suggest that you need to…, that you can't measure sense of self as someone else can generate it. So, for example in advanced dementia if some people are not capable of describing their identity, is it valid and useful as an alternative to ask their relative or carer for what they think is important to that sense of self, and whether your tool, because I didn't notice that being part of your model, and I wondered if that was something you'd decided not to do?

RB: My aim is to ask people themselves, that's the important part of my philosophy, or my ethos is to actually ask the person themself.

CR: So that's very deliberate, so I just wondered, is that in some way what makes your measure stand apart from what other people have used? Is that a novel aspect of it or do other people do that?

RB: I think it's probably novel, yes.

CR: That's great.

RB: What do you think are the main challenges to producing this interview based measure?

CR: So interview-based measure in that you're not going to be getting people to do experimental tasks, that's the thing? Well, first of all, it's the challenge, I keep trying to

think what this word is, but the sort of, not dichot.., anyway. The conflict maybe, something like that between on the one hand having something that taps into everything in a very sophisticated way, and on the other having something that you can deliver briefly, and by people, you know, if you want your tool to have the maximum impact, and use in care homes, it needs to be something that's not difficult to deliver, and that doesn't have lots of props because that's something that's going to become more expensive and more unwieldy, and more difficult. So, my thought is that if this is the first time you are doing this kind of thing, it might be the best approach to go for the simpler option to start with, and there are things that you could build on later. But you want something that's going to be func…, it wouldn't really be helpful to develop a very complicated tool that never got used. So I think that's the struggle. And my feeling is, that if it's something that starts to get used… It's a novel tool anyway if you are asking people with dementia to describe their sense of self, and I can see from your review that there has not been a lot of efforts to develop those kinds of tasks so I think that's er, rather than trying to do everything, it's better to focus on making it streamlined?

RB: Pragmatic?

CR: Yes, that's it.

RB: Thank you. Do you think it's feasible for me to devise one measure that will cover differing levels of ability or should there be two versions of the measure?

CR: So…I think the one measure is preferable so that you can look at people over time, or you can look at comparing two groups. My background as a cognitive psychologist tells me that it's, I'm thinking experimentally, that you want to be able to look at the same thing, I think, but, having said that, and I think your suggestion to have a tool which, at one point you can continue or do the rest if someone has reached a certain threshold, or reached a certain score, and then only do the rest of it, then you can still compare two sets. So I think there's, I'm not an expert in developing these kinds of measures at all, so if there are ways of doing it that are standard for the field, then that seems fine. But I would be wary of having, say for example, and I know it's going to be longer than this, but 10 questions for someone who's not got advanced dementia, and then completely separate task for someone with advanced dementia, because then you can't compare, not really. You've got to be careful to say that they are matched to a certain extent if you do have different ones.

RB: I know you've already looked at this diagram, and we've talked about this, which is just for reference, so I think you do understand that (showing the' Self Test' diagram) fairly clearly?

CR: Yes.

RB: So is there anything you'd like to ask me about it?

EA: So – I'm pointing at the red boxes which are social constructionism, cognitive, and personality, are they the disciplines..?

RB: Yes

CR: And these are the actual items that might be measured [the blue boxes]? That have been measured in the past, or what you want to measure, or both?

RB: They have been measured in the past, I've based this on the literature review, and this is what I've discovered from the literature review.

Expert Advisor Interview – 'EA2'/31/7/15 (Skype)

RB: I could start by just asking you the questions, or would you rather just go ahead and say what you'd like to say, then – I am happy with what you are most comfortable with.

SS: That's okay. I've got all kinds of stuff here, but I can actually – I can put stuff up on some of the files themselves. I can email them to you

RB: That would be excellent, thank you very much. That's above and beyond what we would hope for. Thank you.

SS: I'm going to have to jump around a little bit because of where you are and where everything else are is on my screen.

RB: I'm happy to go with what you would like to say.

SS: I'll kind of do these things I guess as they kind of pop up. This is with some of the scales, I didn't comment on all of them. I thought that some of my responses to some of these might apply to others, and we can talk about that if you like. The first thing that I'm looking at, that I clicked on here is the Rosenberg Self Esteem Scale. I think this is a comment that I think you'll get. I'm sure I won't tell you anything that you don't know. But … this will allow you to know **that** a person feels this or that way. Do you want to know in addition **why** a person feels this or that way? Because a lot of these scales will never tell you that – we don't get it why with, you know, agree, strongly agree, disagree, strongly disagree, but that just tells you that they strongly agree – but why? **Why** are you satisfied with yourself, or **why** are you not? And I think, that's sort of the…, and **when** are you, or **when** are you not?

RB: Yes, exactly.

SS: There are nuances and that's why I think these scales themselves may be beginning points for conversation.

RB: Yes.

SS: Because then, if it were me, and I'm trying to put myself in the place of a person with dementia, if you asked me one question about X and I answer it, and now you ask me a question about Y, I still may be back on X because I've been pondering…, it stays with me, and it might interfere with my answering the next one, and so that's why I think some conversation needs to be built into these things, because it's not like you and me answering these things. And automatically just go into the next one, okay, I'm finished with that one, now I can….this one. Does that make any sense?

RB: Yes, definitely, yes.

SS: Especially self-esteem, you know, these questions are powerful questions. "At times I think I am no good at all". Well, I feel that way sometimes. Well, when do you, when do you? And why do you, why do you feel that way when you do? That's when you might get at all kinds of issues that will arise in relation to other things that you could talk about in other ways.

RB: Yes.

SS: It's with my family, or I don't feel bad about myself when I'm in my support group. You know, but when I go home and they start asking me all these questions like "what did you have for breakfast?"…you know…does that make some sense?

RB: Yes, yes.

SS: So there may be sort of qualifiers to…"I feel useless at times", yes well, I do, well "When do you feel useless?" "When I…". "When don't you feel useless?" "At times" doesn't mean always, it means at times, so…"I wish I could have more respect for myself". Well that might trigger something like "I wish other people had more respect for me, actually". "What would it take?", you know "How…?", "I really wish I did still respect myself; I used to, but I don't any more". Well, why not? What's that about?

SS: Does that make some sense?

JO: It makes good sense doesn't it because if you're trying to understand what's helping someone retain a sense of self, or what's eroding someone's sense of self then those setting conditions are really valuable to know about.

SS: Yeah, and the answers to some of these questions will fit with your larger scheme, I'll get to that in a little bit. Let me kind of move this one away, and we've got another one… here's this one, this is the Tennessee Self-Concept Scale II. I love some of these things, you know. I wonder who makes this stuff up?

RB: This is an old one isn't it, the Tennessee Self-Concept Scale.

SS: Yeah, and some of this stuff…I think, to me, these are all beginning to conversations.

RB: Yes

SS: This…people do this, and they want to quantify, so this thing can help you quantify, so the question I have at the top of this is [reads]… "widely used measures…enables easy scoring procedure"…that's the key…so at the top I said "Now, or always, or at one time?" These can change with age, you know. These are descriptive statements. "I have a healthy body". Well, "I used to", or…

RB: And "healthy" can mean different things anyway. I mean you might be sort of quite physically fit, but just not feel well.

SS: "I am full of pain and suffering". Well, umm, yeah, "especially when I have to be confronted with people who are asking me questions all the time, like this". You know… "I am……person". Well, "Yes, except when people start getting on my nerves about…" That's what I think, it's almost like a Rorschach Ink Blot test, you know. You look at these statements and that could trigger all kinds of stuff that you weren't necessarily… "I'm not important". Well, to whom? "Are you important to yourself? Are you important to your family? "Are there any people to whom you are important? And "When do you feel that way?" and "When don't you?" Well, "I don't feel important when I'm in the doctor's office and they ask me 'What just happened yesterday?' "Well my doctor was talking to my daughter as if I weren't there". You know. So this could be… I guess my overarching point I'm trying to get at here is that many of these statements could be situational, and that's why…, that's the social component of all this, that it's the whole situational thing going on here and you want to know what those situations are because that's part of, I mean, that's part of what affects a person's sense of self.

RB: Definitely

Expert Advisor Interview – 'EA3'/7/8/15 (Skype)

RB: Could you tell me from your experience the ways you observe people, and the ways they express self?

PK: I can speak to this tension, I was recently involved in a study that, CS was involved in that study as well that evaluated 'elder clowning' in dementia care, and it was a very interesting study. I can talk about why I turned to the arts, and why I think the arts are so promising as a means of engaging people living with dementia, but I mention it only because I'm acutely aware of the tensions between qualitative explorations of self-expression and quantitative measures. This was a mixed methods study and so the qualitative piece of this involved video-taping all of the interactions between the residents living with dementia and the elder clowns to help us analyse the impact that this was having. And we also interviewed the clowns, and staff and family, and then we had a whole series of measures to try to capture impact. So we used Dementia Care Mapping, which is why CS was involved; we used the neuropsychiatric inventory, nursing conversion (?) and we had the Cohen-Mansfield Agitation… anyway, a whole bunch of measures. I mean I teach qualitative methods and have long been aware that they are not just methods, they're tied to a paradigm…. differences in assumptions, right? So I don't know why I hadn't really thought through that of course it would be the same for the quantitative measures. But I experienced this acute tension when I went to write up the quantitative data because the assumptions underpinning those measures are that these are all symptoms of dementia, which I actually don't believe. I think that a lot of these are responsive behaviours and so even writing about it became a…I sort of had a bit of an existential crisis because I thought, I don't know if I can say this. You know, all my publications run contrary to this assumption, so when you contacted me with that information, it sort of came right at that time, and I thought, oh, wait a minute, I don't know if I can translate the embodied work that I have done, which I'll describe for you, I don't know if I can translate that into a quantitative measure.

RB: That's our job…[Internet connection broke]

PK: Technology was brilliant, it just hit at my existential crisis.

SS: But we heard everything, you were telling us about how our email came at that time when you were thinking about the appropriateness, or the difficulty…

PK: Just because you mentioned that you were aware of tensions in the discourses, between discourses on selfhood, and I think that what I was explaining was my acute awareness of tensions between particular discourses of self and the whole approach to measuring self, because measuring itself is tied to a particular discipline, and so I just wasn't sure…I'm more than happy to share with you my work. I just wasn't sure in what ways, or the extent to which it could inform the development of a measure of self. Even DCM, which came the closest for me, to something that could capture the kinds of ??…..that I've seen in my own work, I thought was problematic for various reasons so maybe we should just have the discussion and then if we feel that there's more that I can do to inform the project, then we can talk about that.

RB: Yes, that's fine. It is your experience and your observations that I'm really interested in. And I do appreciate that to produce a measure is problematic. I spoke to SS [EA2] last week and he said that it's a big challenge. But I think…I want to try…

PK: Yes, and I think we need better measures. I think that it's an ambitious undertaking, so I applaud you. I'm not sure how I can manage those disciplinary tensions. Ultimately one has to accept that there's going to be compromise. What that looks like, and what the implications of that are for what you want to achieve, I don't know.

SS: I think that's a fair overview from our perspective. We're very familiar with observational tools like DCM. It's not a thing that could come out of our background in cognitive psychology, broadly we feel comfortable with some of the cognitive frameworks of the…even myself as a cognitive psychologist, I'm not comfortable with some of the ways which we approach understanding people living with dementia from a cognitive discipline perspective, so I think, there are tensions there, because people don't come with a mini-mental score within this range without any other co-morbidities and sometimes the discipline makes the assumptions that they do. So I think it's good to have your input from that perspective.

RB: There's one phrase I found in one of the key cognitive papers said that if somebody is talking nonsense or repeating themselves that means they don't get any score. And I thought that was awful. Who says it's nonsense, and if they are repeating it, that probably means it's important. So that's…does that explain where I'm coming from? I want to try and understand people really.

PK: Yes, that's interesting, I've written a couple of different papers in which I've explored how there can be meaning in incoherence. That's challenging enough to capture through observation, let alone some kind of a questionnaire, so I certainly appreciate your perspective and given that that's your philosophical stance I can understand why you'd be interested in hearing more about my work. So the challenges lay ahead, but put those aside for a moment, and maybe I can tell you…do you want me to tell you about the notion of embodied selfhood?

RB: Yes, just what you feel is important and would be helpful, then that would be helpful, thank you.

EA: Well, I can speak more generally if you want about embodied selfhood…

RB: Have you seen how it's expressed? Yes, that would be useful…

EA: So, how has it been expressed? So, the theoretical concept emerged from all the observational research that I've done for many, many years in long-term care homes, and so I have found that there are multiple manifestations of embodied selfhood. So, for example, I looked at how selfhood is expressed through preferences, food preferences. So if someone pushes away fish for example, and we learn that they never ate fish before, they don't like fish, then if you don't have that biographical information, then you might assume that it's just aggressive behaviour, throwing food on the floor. But it takes on new significance if you have that information, so food preferences…more basic types of expression. Gestural expression…so I have a very complex analysis of the importance of the body for gestural communication. The way people with dementia use gesture as a way to compensate sometimes for what they are not able to express verbally. We do it all the time, we use gestures for conversation all the time, and so I see that as being a very significant dimension of communication. There have been a number of studies where I've looked at how self is expressed through religious practice. So I did a study in an orthodox Jewish facility where there was a really powerful example of a male resident who had lost the ability to put a sentence together, and yet, on this particular holiday where they celebrate the Torah, it is an honour for the male congregants to be asked to say a prayer and I remember when I was observing this, I thought this is going to be a disaster, he's not going to be able to do this. Well as soon as they called his name, his whole disposition changed; he walked with pride up and he spoke with absolute proficiency. So, the way that I analysed that was that there's something significant about the orchestration of the event that elicits selfhood. So if you had him in his room for example, and you asked him to recite the prayer, he wouldn't be able to do that. So there's something about being in the synagogue, the presence of the Rabi, the touch of the Torah, the song

from the congregants, there is this orchestration that is very significant. So I mean, this is an important piece for how we approach measurement, because of course it's completely decontextualized, and we're not benefiting from all that the environment has to offer in terms of supporting selfhood. So I thought that's a very powerful example. The other area where I've seen self-expression, very powerfully is through creativity. So singing, dance, painting, the way that people with dementia engage with music is very powerful. So they could have no speech at all, and yet the way that they are engaging with their bodies demonstrates a kind of proficiency and so how you capture that through measurement, I'm not sure? I'm going to keep putting these cautionary notes out because I don't know, but these are the prominent ways in which I think selfhood comes to be expressed through the body.

Appendix VI: Summary of Responses for Each Measure Sent to Expert Advisors

Measure	Questions	Comments EA1	Comments EA2
The Autobiographical Memory Interview (AMI)	**5.**What are your first thoughts about the measure and how applicable it is for people with dementia?	- One of the tasks I am using with people with dementia now. - It is quite a long task and it's very restrictive, e.g. a lot of the episodic score refers to a wedding day and if people haven't got married, have to ask about a friend's wedding – which can be problematic because why would you necessarily remember a friend's wedding? Then score would be low. It is a nice measure in lots of ways, but potentially giving people a lower score than would be fair. - Big fan of the rating scale – it's a neat way of looking at specificity. - Includes assessment of semantic facts which maybe particularly important for supporting identity. - Used as specified in manual – goes through each lifetime period, ask for semantic facts then episodic memories.	Questions asked are 'on command', e.g. "Tell me about X" but people may not be able to relate all the details at once. At a later date they may tell the same story, with something new added. So you may only get a snapshot at a particular time. You may ask about X, but they start talking about Y so how do you score?
	6. Do you think the measure relates to a holistic view of self or specific aspects of self, with reference to the diagram?	- I agree with the diagram. It also taps into aspects of family and friends and occupation because it asks for information about your job, wedding and children, so it taps into "I am…" statements that are social. - There's not really anything about personality. - I don't think people are ever asked about emotions, which is probably deliberate. - Not really a measure of self, just an autobiographical memory measure.	
	7. Do you think the test could be adapted		

AMI (cont.)	so that it does not have to rely so heavily on verbal communication, for example by using pictorial cues, or objects, or actions?	Yes, e.g. Clive Waring playing the piano would show he knew he was a piano player as a semantic representation of his identity but not necessarily that he has memories of specific times. [Using pictures with sounds as prompts] How would you score it? You'd have to have very clear instructions. Re semantic facts – they are there or not there. They are not scored. Re episodic score – ranked – the more 'semantic' the score, the poorer memory is rated. Need to decide which section of AMI will be used (or both). Re using pictures – would certainly be useful for the semantic section. Would be a nice prompt and could help people access more specific memories with sounds and pictures. I cannot think of any section of the AMI that this would not work for. Could capture semantic/episodic nature by scoring verbal responses, but how would people with limited vocabulary be scored? You could show images and ask people to point to ones that are most appropriate for them – but would require a lot of material, and would not be able to distinguish between semantic/episodic memories.	Photographs can help
	8. Do you have any comments about the instructions for participants and the methods of analysis?	The instructions are quite clear, you get told what to say as the assessor – but if people haven't been married or don't have children there is no other response they can give. Nephews, nieces etc. may not be as anchored in memories as their own children would be. [Could we choose which questions to ask, perhaps just the	

AMI-Extended		less specific ones?] – the challenge is whether you need something standardised or start by asking people for things that are important about them. The challenge is how to compare peoples' scores if they start off with different facts that they then expand on.	
	This is the same as the AMI but with an additional middle-age section. Do you think this would be useful?	Do you know what the questions are for the extra section – a holiday that they went on? It's difficult because you start making assumptions about what people's lives are like and the things that most people typically do, and you end up potentially scoring people low when they don't have those memories or identities.	
The Autobiographical Interview (AI)	**5**. What are your first thoughts about the measure and how applicable it is for people with dementia?	A useful measure for tapping how specific people's memories are, and if there are lots of probes you are going to give people the best chance possible to generate details so you don't underscore people – it might be that people have more specific memories with more probing and cueing. It sounds like it is good from that perspective – supporting retrieval. But you only get 5 memories so you get information about how rich the memories are – so it's good for specificity but I don't think this is part of what you think is important for identifying self, and there's a lot of effort involved in probing, and you need a lot of training to do this properly. You can't just deliver it, you need to know what you are doing.	
	6. Does the measure relate to a holistic view of self or specific aspects of self?	Not a measure of self, more an autobiographical memory measure – but this is an aspect of self if you take the view that self is in part based on autobiographical memories.	

The Twenty Statements Test (TST)	**7**. Do you think the test can be adapted so that it does not have to rely so heavily on verbal communication? **8**. Do you have any comments about the instructions? **5**. What are your first thoughts about the measure and how applicable is it for people with dementia? **6**. Does the measure relate to a holistic view of self or specific aspects of self?	No [There are a lot of instructions] So one problem for people with dementia might be if their short term memory isn't very good, they might have forgotten the instructions which are quite hard to follow. - I like this measure – it is much more of a self measure than the other two and I think that it is useful for people with dementia. - I've been using a Ten Statements version, and a lot of my participants weren't able to generate the full ten, so twenty might be a real challenge, and it might make people anxious. - [Do you think you can get enough useful information out of ten?] Yes, it depends what you then go on to use the statements for – you can look at the memories that go with them. - I have shown that the ones generated earlier in the list are most important for self. Depending on how people answer it, it could certainly tap into all the aspects of self in the diagram. I think it is a measure of semantic autobiographical memory – the statements are nuggets of semantic autobiographical memory. So if it's a self task, it's also a sort of autobiographical memory task – these are not episodic memories – it's not that kind of detail. They are semantic	

TST (contd.)		facts, and that has to be in the instructions. In terms of social and personal, it depends on what people generate – you can code them to compare types of statements. You can structure or scaffold by using prompts, e.g. to generate personality statements – so there are two ways of doing it.	
	7. Could the test be adapted so that it does not have to rely as heavily on verbal communication?	- I think so – by using pictures. - But - the great thing about this test is that it is open-ended which means that whatever is important to a person will come out through the statements. But if you give people images, although it helps people who can't verbalise their responses, you don't have access to what's really idiosyncratic to them, and you can't capture it. -Scoring – if someone doesn't point to a picture, does it mean they don't know, don't understand the task, or do they think it's too simple? - Difficult to choose between activities, may want to choose them all? - It's difficult, but there is lots of scope for doing something creative with "I am…" statements.	
	8. Did you find the instructions were suitable for people with dementia?	Yes, but some of all of the older people found it a bit strange to be asked "Can you describe your sense of self?" because it's not something that people do with "I am…" statements, so it might be useful to give examples, but you have to be very careful to give the same examples to everyone because you are priming people to generate certain things. -Instructions are really important, but it does work.	

The IMAGE Test	**5**. What are your first thoughts about the measure? **6**. What aspects of self do you think this is measuring?	- I think it's a measure of how happy or how positive people feel about themselves because the statements all have a direction, positive or negative. - Is it a measure of people's ability to describe themselves, or how happy they are about themselves? - Does saying you have a particular characteristic 'some of the time' mean you have a lower sense of self than someone who said all of the time – that is a bit problematic – characteristic may different on different occasions – e.g. sociability.	
The Questionnaire of Self-Representation (QSR)	**5**. What are your first thoughts about the measure?	- I think it's about how positively people view themselves – it is hard to say whether someone has a sense of self, or the strength of it. - It taps into identity. - I'd be interested in what the mid-points are – I'm inclined to think that there is nothing necessarily wrong with someone's insight if they don't agree outright with something. - "Sometimes I get angry" may be a little clearer because it's acknowledged it's not all of the time. - This might be quite difficult for people with dementia because some of the statements depend on memories, e.g. "I was not good at games or sports" and some of them are quite complex like "the last thing I do before leaving the house is to look at the mirror". - "I am generally attentive to my inner feelings" - that's	

QSR (contd.)	**6**. Does the measure relate to a holistic view of self or specific aspects of self?	quite a hard thing to reflect on. They are difficult questions. - If I was feeling a bit unsure about how to answer the question I'd be tempted to go for the mid-point response which would mean I'd be scored as someone with a weak sense of identity. It covers quite a few things, e.g. your memory, social things like spending time with other people, and personality (e.g. "I feel happy most of the time") so it's quite nice in that respect. I think it's quite a nice tool, but how you score it is problematic.	
	7. Could the measure be adapted so that it does not have to rely so heavily on verbal communication? Do you think the visual analogue scale would work?	That's difficult. If you show people images, how would you rate them? Would it be like a big cross or a tick, and somewhere in the middle? It's quite hard to have a picture representing some of the time, and what does it mean if someone says "some of the time"? I think it would work, but what does it mean if people are in the middle? It doesn't really say, but I imagine that they would be – "How much does each statement describe you?" I think that's fairly clear, that's a good one. Good – I use this kind of measure.	
	8. Do you think the instructions are appropriate for people with dementia?		
The Oral I-AM	**5**. What are your first thoughts about the	The same as the Twenty Statements Test. It is holistic	

Test	measure and how applicable is it for people with dementia? **6**. Does this measure relate to a holistic view of self or specific aspects of self? They had a slightly different way of analysing it. Do you think this would be useful for our measure? **7**. Could the test be adapted so that it does not have to rely as heavily on verbal communication?	because it allows people to talk about personality and social stuff. It depends on what they generate as to what it taps into. If they asked people to generate memories afterwards it taps into autobiographical, so I'd say 'holistic'. It depends. If ultimately you want a measure of self that people are going to use in care homes, are you interested in whether people talk more about physical than personality? Maybe you don't need to go that far with it. Potentially, but it would be difficult. In many ways it is the same as what I do in terms of the "I was…" and "I will be…" so I think it's applicable. It enables you to look at autobiographical memory, and memories that are important for identity, and the "I am.." statements are a useful way of tapping into self-knowledge.	
The 3-I Test **The 3-I Test**	**5**. What are your first thoughts about the measure and how applicable is it for people with dementia? How do you think the "I am…" and "I was…" differ? Did you find that when people were answering "I am…" they sometimes went into "I was…"?	We asked people not to. We asked for things that people thought were enduring aspects of their identity, the emphasis was on how people were now, and that's how people were answering it. "I was…" and "I will be…" are interesting – I've done a bit of work on "I will be…". It is quite an important aspect of identity to be able to project into the past and into the future. So that would be quite an important thing to include, but it's not really part of the model. Perhaps include 'mental time travel' under autobiographical, to reflect going forwards and backwards which might be an	

(contd.)		important aspect of having a sense of self. So this test is good for tapping into that. Yes	
	7. Could the test be adapted so that it does not rely as heavily on verbal communication? Could you do that with future thinking?	You can give people a fixed set of pictures, and ask them if they agree or disagree with these things, but what are you going to show people? Or you could ask "Will you be doing these activities tomorrow?" and show pictures of people eating and things like that, to make it relevant for everyone, but then it becomes personally less significant because you are not tapping into identities, you are tapping into activities. I think yes, but maybe not to the extent that it has to be in your measure, because you are not going to have everything in. And I don't know how you are going to score it.	
	Could we see future thinking as something over and above the "I am…" task that is very important for measuring self?	If people can't generate facts about themselves in the future, what does that mean, and they will have to be verbal responses if you ask people what are you going to do tomorrow, or next month, or next year, and you can't do that. It is, because it's not "I am…" related but it's still thinking about yourself in the future, which is projecting, but if you have to show pictures you are not necessarily tapping into someone's ability to say what they are going to do tomorrow if they just point to a picture of eating. I don't	Now, or always or at one time? These can change with age, e.g. "I have a healthy body". Well, "I used to", or "I am full of pain and suffering". "Especially when I am confronted with people asking me questions all the time", or "When people start getting on
The 3-I Test			

(contd.)

Identity in Dementia Questionnaire (SIDQ)	They [researchers] have asked family members or carers what they thought the most important roles were, and then they would ask the people with dementia themselves, and then compare. But I would just use it for the own view of people with dementia, and they would rate how important they feel they are or were, on a 5-point scale. Then I would show a list of activities and ask what activities they like or liked and were not able to do. Do you think that's quite simple and straightforward? And it brings in personal attributes (traits) and how much they felt themselves or family members had achieved during their life. **6**. Do you think the measure relates to a holistic view of self or specific aspects of self? **7**. Could the test be adapted so that it is does not have to rely as heavily on verbal communication?	That's quite a nice way of looking at it, you get what's important to the individual and I think that's really good. What's lacking in some of the other scales is that you are not really getting a picture of what people think is important to them. So it's not open ended, but I prefer the way it's phrased. Yes, that seems straightforward. That's a nice positive spin, I like that. Holistic, because to answer these questions you need to have semantic and autobiographical memory, and it taps into traits and a lot of social aspects, so it seems very good. It sounds like it could with pictures, getting people to point to what they are most proud of. But as soon as you start looking at specific memories, it's difficult to have a task that's non-verbal. But this is a nice starting point for that. It is open-ended but it's a different kind of task. With the "I am…" task you could look at how many things people generate and the nature of those items, so you're going to	
SIDQ (cont.)			

	Do you think the “I am…” task adds anything over and above the test? How would you score this side of it? Is it a presence or absence score rather than a quality score? The purpose of it is not suitable really what we want, but there may be aspect of it that can be used in other ways?	get other types of information from it which may not be the kind of task you want to do. This one seems more constrained, easy for people to deliver. What kind of scores doe it generate? And is it meaningful? Yes, a problem. As soon as you start making this an objective measure, if someone doesn’t like doing any of these things, it doesn’t mean they don’t have a sense of self. It just means they don’t like doing these things. Yes, you could pick some of these things out, and if you wanted to have pictures as “I am…” statements you could use this as the basis of those pictures – a lot of these things [activities listed] are relevant to people in this age-group. Ask “Do you like doing this?” on a Visual Analogue Scale and people could point at that. But how are you going to score it? It’s still what do your scores mean? If someone says “I really like needlework” what does that mean? I think it’s fairly straightforward and it’s been developed for dementia so I’m sure it’s been simplified as much as possible. This is a bit like the PANAS (Positive and Negative Affect Schedule) – how creative you are. That’s not really relevant to what you want to do is it?	

	8. Do you have any comments about the instructions?	This could be an important aspect of self but you are going to end up with a very, very big questionnaire if you try and do all of these things.	
The Creative Personalities Scale	**5**. What are your first thoughts about the measure and how applicable is it for people with dementia?		
The Sense of Belonging Scale	**5**. What are your first thoughts about the measure and how applicable is it for people with dementia?	I have used this with Alzheimer's participants. It's about optimism. They are able to do it but it's hard for people to remember the numbers. Yes, I think that would be the right kind of thing to do. It's nice because it's short – I've used this as a wellbeing scale. No, that's not a problem - you just need to know what you are doing so you can reverse scores afterwards.	-"I feel comfortable talking in my group" : What group? Why assume that people have a group? - Why not ask them if they feel they belong to one or another group? - Perhaps they used to belong to this or that group but don't any longer. - Perhaps they would like to say why they feel that way
The Life Orientation Test (LOT)	**5**. What are your first thoughts about the measure and how applicable is it for people with dementia? So could we use the Visual Analogue Scale? This has reverse scoring, do you think that	Yes. The trouble is that as soon as you take someone's scale and you change it then it loses some of its validity so I would be very wary of chopping and changing all these different scales. So you could just choose a few and focus on those.	

	would be a problem if we used the Visual Analogue Scale? Some of the questions are fillers. Is that how you treated it as well?	Is self-esteem what you want? I think you could arguable say that's a very big thing and your test is not about self-esteem.	
The Rosenberg Self-Esteem Scale	**5**. What are your first thoughts about the measure and how applicable is it for people with dementia?	Not many people talked about physical things because I asked them to talk about long term and enduring aspects of their identity so often it was roles and social relationships. It also seems more of a wellbeing scale. I think you could tap into other aspects of self by using other tasks.	-This will allow you to know that a person feels this or that way. Do you want to know also *why* a person feels this or that way? We don't get that with rating scales of agree strongly, disagree etc. - Also when and where are these statements applicable? - There are nuances and that's why I think these scales may be beginning points for conversation. - Self-esteem questions are powerful – when, and why do you feel that way? - You may get all kinds of issues that will arise in relation to other things that you could talk about

The Physical Self Scale	**5**. What are your first thoughts about the measure and how applicable is it for people with dementia?		in other ways.

Appendix VII: Standard Occupational Classifications

Occupational Categories	Specific Occupations	Occupational Categories	Specific Occupations
Managers and Directors	Manager Executive Army/Air Force Officer Health and Protective Services Managers Business owner	**Skilled Construction Trades**	Builders Roofers Plumbers Carpenters Painters and Decorators Weavers and knitters Upholsterers
Professional Occupations	Scientist Engineer R and D Health professionals Optician Pharmacist Dentist Therapists Nurses and Midwives Teachers Lecturers Lawyers and Barristers Accountants Architects Surveyors Social workers Librarians Journalists		Tailors and Dressmakers Cobblers Printers Butchers Bakers Grocers Florists Furniture makers
		Caring Service Occupations	Nursery nurses Childminders Teaching assistants Veterinary nurses Nursing staff Ambulance staff Dental nurses Residential wardens Care workers Undertakers
Associate Professional and Technical	Technicians Draughtsmen Paramedics Community workers Police, Fire and Prison Officers Artists Musicians Dancers Authors Theatrical Designers Sports Occupations Pilots Financial Occupations Sales executives Estate Agents Auctioneers	**Leisure and Travel Services**	Travel Agents Air Hostess Hairdresser/Barber Beautician Housekeepers Caretakers
		Sales and Customer Services	Sales assistants Debt collectors Delivery persons Market Traders Telephonists
		Plant and Machine Operatives	Food and drink operatives Manufacturing operatives Coal miners Quarry workers Road and rail construction Lorry Drivers Train Drivers and Guards Bus and Coach Drivers Driving Instructors Taxi drivers Crane drivers Fork-lift Truck Drivers
Administrative and Secretarial	Local Government Book Keepers Bank and Post Office Clerks Library assistants Office Managers Secretaries Receptionists Typists		
		Administrative and	Farm Workers Forestry Workers

Skilled Trades	Farmers Horticulturalists and Gardeners Fishermen Metal workers Mechanics Electricians Telecommunications	**Service Occupations**	Postal workers Window and Street Cleaners Domestic Cleaners Security Guards School Crossing Wardens Catering Assistants Parking Wardens Hospital Porters Waiters and waitresses Bar Staff Leisure Attendants

Appendix VIII: Tables of All Stimuli Presented in the Pilot study

1. Activities

Slide	Activity	Slide	Activity
	Hobbies		**Indoor activities**
1	I am a knitting and crochet expert	28	I am a good cook
	I am a sewer	29	I am musical
2	I am a lace maker	30	I am good at household chores
3	I am a potter	31	I am a player of puzzles and board games
4	I am a woodworker	32	I am a good reader
5	I am a collector	33	I am a good shopper
6	I am a model maker	34	I am a family person
7	I am a steam enthusiast	35	I am a television watcher
8	I am a photographer	36	I am interested in the news
9		37	I am an animal lover
	Sports	38	I am artistic
10	I am a cricket fan		
11	I am a football fan		**Social**
12	I am a rugby fan	39	I am a religious person
13	I am a tennis fan	40	I am sociable
14	I am a bowling fan	41	I am a dancer
15	I am a golfer	42	I am a fan of eating out
16	I am a fan of athletics	43	I am a cinema-goer
17	I am a snooker fan	44	I am a theatre-goer
18	I am a darts fan		
	Outdoor activities		
19	I was a runner		
20	I am a walker		
21	I was a cyclist		
22	I was a fan of camping or caravanning		
	I was a driver		
23	I am a fisherman		
24	I am a gardener		
25	I am a traveller		
26	I am a swimmer		
27			

2. Traits and physical characteristics

Slide	Traits and physical characteristics
	Abstract
1	I am always busy
2	I am punctual
3	I am curious
4	I am funny
5	I am happy
6	I am lazy
7	I am helpful
8	I am calm
9	I am anxious
10	I am shy
11	I am lonely
12	I am thoughtful
13	I am forgetful
14	I am smart
15	I am honest
16	I am clever
17	I am healthy
18	I am well mannered
	Concrete
19	I am short
20	I am tall
21	I am thin
22	I have a large waist
23	I had brown hair
24	I had blond hair
25	I had auburn hair
26	I had black hair
27	I have wrinkles

3. Relationships and Occupations/male

Slide	Role, Relationship, Occupation	Slide	Occupation
	Relationships	29	I was a cleaner
1	I am a brother	30	I was a traffic warden
2	I am a son	31	I was a waiter
3	I am a father	32	I was a barman
4	I am a grandfather	33	I was an office clerk
5	I am a husband		
			Skilled trades
	Managerial, directors, armed forces	34	I was a farmer
6	I was a manager	35	I was a gardener
7	I was in the forces	36	I was a mechanic
		37	I was an electrician
	Professional occupations	38	I was a welder
8	I was a scientist	39	I was a builder
9	I was a doctor	40	I was a plumber
10	I was an optician	41	I was a painter and decorator
11	I was a dentist	42	I was a tailor
12	I was a nurse	43	I was a shop worker
13	I was a teacher	44	I was a chef
14	I was a lawyer		
15	I was an accountant		**Leisure, travel, customer service**
16	I was a vet	45	I was a pilot
		46	I was a barber
	Associate professional and technical	47	I was an actor
17	I was an engineer	48	I was a salesman
18	I was an architect		
19	I was a surveyor		**Plant and machine operatives**
20	I was a librarian	49	I was a miner
21	I was a writer	50	I was a driver
22	I was a police officer	51	I was a heavy machine operator
23	I was a fireman	52	I was a forestry worker
24	I was an estate agent		
	Service and administrative		
25	I was a postman		
26	I was a milkman		
27	I was a dustman		
28	I was a security guard		

4. Relationships and Occupations/female

Slide	Role, Relationship, Occupation	Slide	Occupation
1	I am a daughter		**Administrative and secretarial**
2	I am a mother	31	I was a secretary
3	I am a grandmother	32	I was a receptionist
4	I am a wife		
5	I am a sister		**Skilled trades**
		33	I was a gardener
	Managerial, directors, armed forces	34	I was a seamstress
6	I was a manager	35	I was shop assistant
7	I was in the forces	36	I was a cook
	Professional occupations		**Leisure, travel, customer service**
8	I was a scientist	37	I was an air hostess
9	I was a doctor	38	I was a restaurant manager
10	I was an optician	39	I was a hairdresser
11	I was a dentist	40	I was a housekeeper
12	I was a therapist	41	I was an actress
13	I was a nurse		
14	I was a teacher/lecturer		
15	I was a lawyer		
16	I was an accountant		
17	I was an architect		
18	I was a vet		
19	I was a surveyor		
	Associate professional and technical		
20	I was a librarian		
21	I was a writer		
22	I was a police officer		
23	I was an estate agent/auctioneer		
	Service and administrative		
24	I was a postal worker		
25	I was a lollypop lady/dinner lady		
26	I was a cleaner		
27	I was a care worker		
28	In was a traffic warden		
29	I was a waitress		
30	I was a barmaid		

Appendix IX: Observational Methods, Key Reference Studies and Comments About Relevance to Measure of Self

1. Behavioural Analysis	
i) Oyebode et al, (2008)	Behavioural analysis of coping.
Background/aims	Developed as alternative to self-report for people with moderate AD who may not be able to complete interviews and questionnaires.
Participants	2 groups: 12 ppts with mild AD and 12 ppts with moderate AD
Methods of data collection	Video-taped responses to 7 everyday tasks. 3 stages of analysis: 1. Detailed transcripts of videos to provide comprehensive list of responses for each task. For people who did not wish to be filmed detailed description of verbal and non-verbal responses listed. 2. List of coping behaviours grouped into categories with clear definitions for each category. 3. Descriptive and statistical analysis of distribution of categories and differences between groups.
Number of categories of observed behaviours	Seven categories relating to coping strategies: effort-self, effort-other, positive acknowledgement, negative acknowledgement, concealment, avoidance, ambiguous.
Method of reporting data	Total number of coping responses for each task; analysis of whether some responses used more than others.
How reliability of method was assessed	Initial pilot study with 3 ppts with memory problems, but not dementia. Inter-rater analysis to assess consistency of list of coping behaviours and category groups.
Comments	Behavioural categories decided after viewing videos; method described for people who do not wish to be videoed.
ii) MacPherson et al, (2009)	Behavioural analysis used to assess art gallery access programme.
Background/aims	To analyse engagement during activity sessions; to quantify rich observed behaviour into categories to enable statistical analysis.
Participants	15 people with dementia, able to hold at least a simple conversation. Two groups: community dwelling and in residential care
	Videoed 45 to 60-minute activity sessions over a 6-week

Methods of data collection	period. Films observed and coded to give operational definitions of behaviours that were indicative of affect. Time-sampling method: 5 secs 'on'=watching participant; 5 secs 'off' = coding predominant behaviours from the previous 5 seconds.
Number of categories of observed behaviour	Four categories of behaviour: 1. Negative, e.g. withdrawn, distracted, fidgeting. 2. Neutral, e.g. unclassifiable, being distracted, talking to self. 3. Engaged, e.g. showing interest in stimulus, talking about and/or looking at stimulus. 4. Highly engaged, e.g. laughing, smiling, gesturing, active listening (nodding, leaning to hear better).
Method of reporting data	Proportion of observed behaviour c.f. total time of activity.
How reliability of method was assessed	Two independent raters provided operational definitions of behaviours to arrive at consensus.
Comments	Possibility of using a version of the 4 categories of behaviour/engagement as episodicity rating score of 0 to 3?
2. Functional Analysis	Functional analysis of irrational and rational statements in a person with AD.
i) Beaton et al, (2006)	
Background/aims	To evaluate effectiveness of FA methodology with a person with AD. Authors concluded that FA methodology needs to be revised to better identify function of irrational speech.
Participant	One ppt with AD who was identified as exhibiting irrational speech.
Methods of data collection	Two x 5min sessions, for each of 4 conditions; 20 second partial interval recording; 2 researchers observing.
Number of categories	Two categories of speech: 1. Irrational statements, e.g. statements that referred to stimuli not present in room or not being discussed, preservative speech (repeated words, syllables, or statements). 2. Rational statements, e.g. those that did not meet criteria for irrational speech, statements relevant to stimuli. Instances of laughing and other vocal sounds not recorded as data.
	Agreement between observers if both marked same response

How reliability of method was assessed	as occurring or not occurring in the same time interval.
Comments	Who is to say statements are rational or irrational? Memories may be triggered during the activity that are not obvious to the researcher, but may be rational to the participant. No consideration of gestures, facial expressions etc.
ii) Trahan et al, (2014)	Functional analysis of bizarre speech.
Background/aims	To identify environmental influences that affect occurrence of bizarre speech.
Participants.	Three ppts with moderate to severe dementia who were reported as exhibiting bizarre speech.
Methods of data collection	5 and 10 minute sessions; 15 second partial interval recording.
Number of categories	Three categories of bizarre speech: 1. Off-topic statements, e.g. sentences, phrases, utterances about topics not being discussed. 2. Illogical or ambiguous words within a sentence. 3. Grammatical errors, e.g. pronouns without antecedents, incomplete sentences, fragments or joined sentences. Other data: 1. Statements not defined as bizarre speech. 2. On-topic, intelligent, non-ambiguous statements.
Method of reporting data	Percentage of intervals with bizarre speech and percentage of intervals with other speech.
How reliability of method was assessed	Inter-observer agreement between two observers.
Comments	FA is intended to investigate why behaviours occur; implies behaviours are problematic rather than being seen as idiosyncratic way a person communicates. FA seems to be looking for causes of 'positive' and 'negative' behaviours rather than aiming to explain the meaning of the behaviours.
3 Interaction Analysis	Account of foundations and practice of IA.
Jordan & Henderson, (1995)	IA is an interdisciplinary method for the empirical investigation of human beings interacting with each other and objects in the environment.
Background/aims	Relies on video recordings to enable close observation and analysis of behaviours.

Methods of data collection Stages in analysis of data	Two elements: 1. Content logs or listings – indexed by time to provide overview of data. 2. Transcription of the most significant segments of content logs; level of detail depends on interests of researchers. Speech transcribed verbatim with annotations for non-verbal behaviours. Record data as numbers of occurrences of specific behaviour and duration.
Method of reporting data	Collaborative viewing of videos.
How reliability of method was assessed	No predetermined analytical categories. Too time consuming for my study.
Comments	

Appendix X: Observational Tools that have been used with People with Dementia

Observational Tools	
1. 6-Item Philadelphia Geriatric Centre Rating Scale Lawton et al, (1996)	Observed emotion (affect) in nursing home residents with AD
Background/aims	The 6 item-PGCRS was designed for assessing positive and negative affect by direct observation of participants. Based on 'dual-channel' hypothesis of affect: 1. Positive affect related to engagement in external events, e.g. socializing, recreational activities. 2. Negative affect related to inner phenomena such as memory, thoughts, physical symptoms.
Participants	Two groups: 1. 253 residents of special care units judged to be minimally capable of comprehending consent information. 2. Comparison group of 43 residents without dementia.
Methods of data collection	Ten minute periods observing 'behaviour streams'; extent and duration of affect states rated on 5-point scale: never; < 16 secs; 15 to 59 secs; 1 to 5 mins; > 5 mins. Also a 'can't tell' rating. Not video recorded.
Number of categories of behaviour	Six categories: 1. Pleasure: smile, laugh, touching with 'approach', nodding, singing, reaching out with hand or arm, open arm gesture, eyes crinkled. 2. Anger: clenched teeth, grimace, shout, swear, berate, push, physical aggression (e.g. fist shaking), pursed lips, eyes narrowed, brows knitted/lowered. 3. Anxiety/fear: furrowed brow, restlessness, repeated or agitated movements, facial expression of fear or worry, sigh, withdraw from other, tremor, tight facial muscles, repetitive calling, hand wringing, leg jiggling, eyes wide. 4. Sadness: cries, tears, moans, mouth drawn at corners, eyes/head turned down, face expressionless, wiping eyes, wrinkled forehead. 5. Interest: eyes follow object, intense fixation on object or person, visual scanning, facial, motor or verbal feedback, eye contact maintained, body or vocal response to music. 6. Contentment: comfortable posture, sitting down, smooth facial muscles, lack of tension in neck and limbs, slow movements.
Method of reporting data	Positive states = pleasure, interest, contentment. Negative states = sadness, anxiety, fear. Frequencies and duration of behaviour states.
How reliability assessed	Two interobserver ratings for each affect state.
Comments	Good operational definitions of affect states, could use rating scale method for non-videoed version of measure.
2. Greater Cincinnati Chapter	

Well-being Tool **Sauer et al, (2014)** Background/aims	Modified version of GCCWT used to assess quality of life of people with dementia. Tool used to code intensity and frequency of observed domains of wellbeing and ill-being as evaluation of person centred care and visual arts activities.
Participants	38 ppts with moderate to advanced dementia.
Methods of data collection	Videotaped sessions lasting 40 minutes over 12-week period; coded in 5-min intervals.
Number of categories	Two ratings made for each 5-min interval: Frequency of wellbeing/ill-being: 5=most of the time, 3=some of the time, 1=infrequently. Intensity of wellbeing/ill-being: 5=high, 3=moderate, 1=low. If neither well- or ill-being observed rated as 0. 25 item indicators of wellbeing and ill-being. *Wellbeing domains:* 1. Social interest: interest in others (eye contact, polite smiling), offers support without prompts, acknowledges support, seeks approval/affirmation, initiates conversation, verbal/nonverbal expression of assertiveness. 2. Engagement: sustained attention, requires prompting and cueing, seeks task support, engaged in task-related conversation. 3. Pleasure: smiles, laughs, verbal/nonverbal expressions of pleasure, enjoyment, pride and satisfaction. *Ill-being domains:* 1. Disengagement: neutral passivity, sleeping, staring into space, leaving activity. 2. Negative affect: anger, physical signs of agitation, verbal/nonverbal expressions of anxiety or frustration. 3. Sadness: behavioural signs of sadness, verbalizes feeling sad. 4. Confusion: verbal/nonverbal expression of confusion.
Method of reporting data	Proportion of observed sessions when each indicator demonstrated, for each 5 min interval – i.e. counting number of instances of 'most of the time' and 'some of the time', and 'moderate' or 'high'.
How reliability assessed	Inter-rater agreement following 4-week pilot stage for determining coding descriptions.
Comments	Good operational definitions of behavioural indicators but too complex for my study – intended for extended study periods.
3. Positive Response Schedule for Severe Dementia **Perrin, (1997)** Background/aims	To measure wellbeing in people with dementia over a short time scale.
Participants	

Methods of data collection	Five test phases; 4 ppts with severe dementia. Video-recordings of therapeutic interventions of up to 60 minutes, observing one participant with one carer; 20-sec observational intervals followed by 10-sec data recording interval.
Number of categories	Ten behaviour criteria: 1. Deliberate body movement; exclude involuntary or automatic movements. 2. Deliberate head movement. 3. Vocalization, e.g. speech, singing or unidentifiable noise. 4. Looks at environment not related to activity. 5. Looks at carer, eye contact with carer. 6. Initiates interaction by facial, bodily or vocal gestures. 7. Engagement: any absorbed commitment to activity, e.g. singing, following movements of carer, extended conversation. 8. Happy: smiling, animated facial expression. 9. Sad: down-cast facial expression, mouth turned down, eyes turned down, tearful. 10. Fear: facial or bodily expression of fear, e.g. widening of eyes, rapid head/eye movements, sharp intake of breath, bodily 'jumping' or recoiling.
Method of recording data	Total number of 20-sec time frames with each category of behaviour recorded divided by number of time frames possible multiplied by 100.
How reliability assessed	Inter-observer reliability over 5 test sessions.
Comments	Good range of behaviours and operational definitions. Article includes example of data recording sheet. Is simply counting occurrences of behaviour better than judging frequency?

Appendix XI: Pilot Study Protocol

Research Protocol
Developing an Objective Measure of Self in Dementia

1. Introduction

Self is considered to be a vital and enduring feature of all human beings and preservation of self is considered to be fundamental for wellbeing (Fazio, 2008). It is believed that cognitive impairments associated with dementia lead to change in self and this has been reported as being one of the most feared consequences of dementia (Corner & Bond, 2004). These fears are based on the assumption that because people have difficulty remembering recent and past events they also lose their sense of self (Cohen & Eisdorfer, 2001). However, it may be that memories themselves are not lost and it is access to them that is affected. This is further supported by research which has shown that sense of self can be retained by people with dementia even when cognitive impairment is severe (e.g. Caddell & Clare, 2013; MacRae, 2010; Sabat & Harre, 1992).

Studies that explicitly focus on the lived experience of people with dementia, including their sense of self, have tended to be qualitative (e.g. Pearce et al, 2002; Small et al, 1998; Westius et al, 2010) and have not aimed to measure the extent to which self is maintained. However, the researchers involved with this study propose that observational techniques used by qualitative researchers can be adapted to be measurable and thus integrated with experimental methods to capture the extent of retained self.

The aim of this research project is to produce an objective measure of self that will be considered reliable and robust; therefore, this study will use standard methods for developing and assessing the reliability of measurement tools. The new measure will be based on existing tests of self that have been reported as valid and reliable, but not suitable in their original form for people who have difficulties verbalising responses. Therefore, the selected tests must be adaptable in ways that help people with dementia demonstrate their own sense of self. For example, visual images will be used as prompts for self-descriptions instead of free recall, and observational methods will be used to aid categorisation of participants' responses to the stimuli.

The first requirement of a valid measure is that it has a comprehensive theoretical basis; the new measure of self is based on the framework of self shown in Figure 1 below, which was developed following a literature review. The results of this review demonstrated that self is multifaceted and that links can be made between different disciplines that have sought to understand and identify the components of self. Figure 1 illustrates how components of self are related; the square sections demonstrate different theoretical approaches; the triangular sections represent the multiple components of self that have been investigated in association with the different theoretical approaches.

The materials for the Measure of Self will be adapted from three well establishes quantitative measures of self: 'The Twenty Statements Test' (Kuhn & McPartland, 1954) and the 'Tennessee Self-Concept Scale II' (Fitts & Warren, 1996), which have good validity in populations without dementia, and the 'Self and Identity in Dementia Scale" (Cohen-Mansfield et al, 2000). The new measure will consist of elements taken from each of these according to recommendations specified by prior consultation with a panel of expert advisors in the fields of self and dementia, in order to represent the components of self illustrated in Figure 1. Tasks and activities taken from the measures will be adapted for people with dementia.

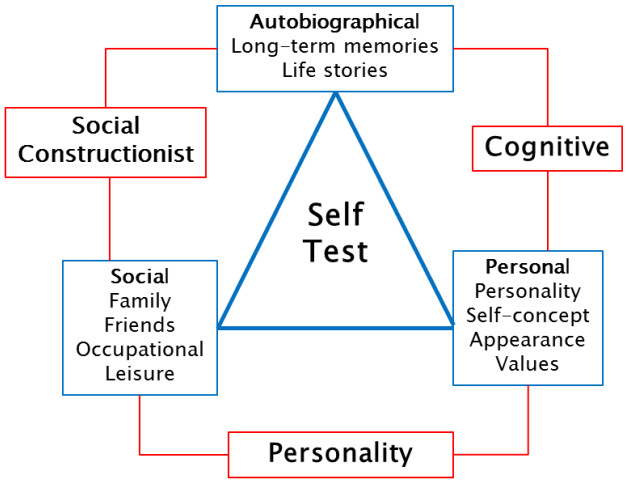


Figure 1: A conceptual framework of self

To summarise the aims of this study are:

- To facilitate the inclusion of people with dementia by ensuring that the new measurement tool will enable people with dementia to provide responses.
- To refine the items that will be used in the measure.
- To develop a scoring framework to characterise the facial expressions and physical gestures of people who have difficulty responding verbally.
- To validate the scoring system used for the test.

The ultimate aim of this body of work will be to produce a measure of self that can be used to evaluate psychosocial interventions and be used as a basis for further research involving people with dementia at all stages of the condition. This study is a pilot to evaluate the feasibility of the new measurement tool. A validation study of the refined Measure of Self will be performed when this pilot study is complete to establish validity and reliability of the methods and outcomes. A second ethics application will be submitted for the validation study.

2. Method

2.1 Participants

Twenty participants will be recruited for the study; this number was determined by following the recommendation of Watson (2013) for a study of this kind intended to demonstrate internal consistency. Inclusion criteria will be:

- Adults with a diagnosis of any type of dementia who have capacity to consent and are residents of care homes or who attend dementia support groups and/or day centres.
- English-speaking and able to understand spoken and written words, with no hearing impairment; people who have impaired communication abilities will not be excluded.
- Vision (with glasses if needed) should be sufficient to clearly view images and words printed on A4 paper.

Exclusion criteria will be people who lack capacity to consent.

Prospective participants will be identified and recruited via dementia support groups, day centres and care homes in the Leeds and Bradford area, with the aim of recruiting from 3 support groups/centres and 3 care homes. Potential sites will be identified first by the researcher contacting care homes and support groups by email or telephone to arrange to visit. The researcher will discuss the purpose and requirements of the study with support group and care home managers, and eligibility requirements will be confirmed. Managers will be asked to display advertising posters and will be given leaflets explaining the project to hand out to anyone who is interested. People who would like to find out more about the study will be asked to contact the researcher directly (contact details will be on the posters and leaflets), ask a relative or friend to do

this for them, or tell staff or managers of their interest. The researcher will contact the support groups and care homes after one week to determine if any attendees or residents have expressed an interest, and if so, arrange to visit again to approach prospective participants personally and provide further information.

2.2. Study design

The study will take the form of one-to-one interviews. Each participant will be interviewed on one occasion, or the interview will be divided into two sections if it is felt that the full interview is too demanding for a participant.

2.3 Background information

Some background information will be collected before the participants are interviewed; specifically, demographic information consisting of date of birth, gender and level of education, and the FAST Scale of functional abilities (Reisberg, 1988) which will be completed by consulting a relative or member of staff who knows the participant well. The FAST scale describes 7 stages of dementia related to physical and cognitive abilities. Stage 1 indicates no cognitive decline, and Stage 7 indicates severe dementia.

The following tests will provide more detailed information about mood and the severity of dementia related to cognitive functioning, and will be administered after the Measure of Self interview.

- The 4-item Geriatric Depression Scale (GDS4, Shah et al, 1997)
- The Addenbrooke's Cognitive Examination III (ACE-III, Hseih et al, 2013)

The 4-Item Geriatric Depression Scale is a self-assessment tool that screens for depression in older adults. The test will take about 1 minute to complete with a score of 2 to 4 indicating possible depression. It is known that depression can impair memory (Williams et al, 2007) therefore depressed mood may affect the way participants respond to the measure of self.

The researcher will only ask participants to complete the ACE-III if they are able to do so without difficulty. The ACE-III will provide detailed information about the cognitive abilities of the participants which will help provide an understanding of how people with different cognitive abilities respond to the Measure of Self. The ACE-III takes about 15 minutes to complete, and measures memory, attention, language and visuospatial function, which are all relevant to completing the Measure of Self. A score of 88 out of 100 indicates suspected dementia.

The researcher will have noted if the participant consented to their interview being video recorded when written consent was given during the recruitment process. On the day of the interview the researcher will confirm verbally that participants who previously agreed to be video recorded are still happy for this to happen.

2.4 Materials

The materials for the new measure will comprise a range of illustrated statements (stimuli) relating to the multiple aspects of self (illustrated in Figure 1), and will be divided into 3 sets and 11 subsets:

Set A: Activities: 5 subsets, with a total of 44 stimuli.
Set B: Traits and physical characteristics: 2 subsets, with a total of 27 stimuli.
Set C: Relationships and occupations: 2 subsets for male and female participants, also with 2 subsets each, totalling 13 stimuli.

Each set will contain stimuli consisting of pictures and written statements starting with "I am…" or "I was…" printed in large font (size 32) on laminated sheets of A4 paper, for example "I am football fan"; "I was a scientist" (see Appendix I for examples).

The 'Activities' set will consist of 44 stimuli taken from the Self-and Identity in Dementia Scale. The 'Traits and Physical Characteristics' set will consist of 27 stimuli taken from the Tennessee Self-Concept Scale II (Fitts & Warren, 1996). The 'Relationships and Occupations' set was informed by the 'Occupation' and 'Family membership' sections of the Self and Identity in Dementia Scale (Cohen-Mansfield et al, 2000), and will be divided into two subsets: one for male and one for female participants. There will be 5 relationships specified for each gender (e.g. father/mother, brother/sister), and 7 categories of occupation (e.g. professional, skilled trades), with an average of 7 per category, taken from the Standard Occupational Classification 2000 (ONS, 2000). Over the whole of the Measure of Self each participant will be presented with a maximum of 84 stimuli, depending on the number of occupations they recall.

There will three response cards: "Just like me", "A bit like me", and "Not at all like me", which will be printed in large font (at least size 56) on cards measuring 21x5 cm which will be used to facilitate the sorting of the stimuli (see Appendix II for examples).

2.5 Procedure

The administration of the Measure of Self will consist of 6 phases:

1. Practice phase
2. Matching phase
3. Review of Matching phase
4. Sorting and Memories phase
5. Review of Sorting and Memories phase
6. Finishing the interview and debriefing

Phases 2 to 5 will be video recorded. If a participant wishes to perform the test over two sessions a suitable division is between Phases 3 and 4. Figure 2 below illustrates the administration of these phases.

2.5.1 Practice Phase

The practice phase is estimated to take about 5 minutes. The researcher will position the 3 response cards labelled "Just like me", "A bit like me" and "Not at all like me" in front of the participant and ensure that the participant can read and understand what each card says. The researcher will have three stimuli (e.g. "I am friendly", "I was a secretary", "I am polite") that the participant can place in front of one of the "like me" cards according to how like themselves they think the statements are. The researcher will read from an instruction sheet: *"I am going to show you a picture. Do you think this picture is like you? Can you place it in front of the card that describes it best: 'Just like me', 'A bit like me', or 'Not at all like me'?"* Participants will either place the stimuli in front of their chosen response, or, if participants are not able to do this themselves, the researcher will look for observational indicators of engagement to facilitate the sorting procedure, (see Section 3.6 for detail).

The researcher will then show the participant the three stimuli, one at a time. The researcher will remind the participant what to do if necessary by repeating the instructions, and prompting by further questions. For example, *"Would you say you are a friendly person?"* Depending on the response the researcher will then ask *"Would you say being friendly is 'a bit like you' or 'just like you'?"* If the participant is unable to respond verbally and does not place the stimuli in front of a response card the researcher will observe his or her gestures and facial expressions to judge where the stimulus should be placed, and place it for the participant. The researcher will observe the participant again to judge if this is correct. If a participant is still unsure about what to do, the researcher will repeat the practice procedure. At the end of the practice procedure the researcher

will ask the participant if he/she would be happy to continue with the rest of the interview. If the participant expresses that they do not wish to continue the researcher will thank the person for helping and terminate the session.

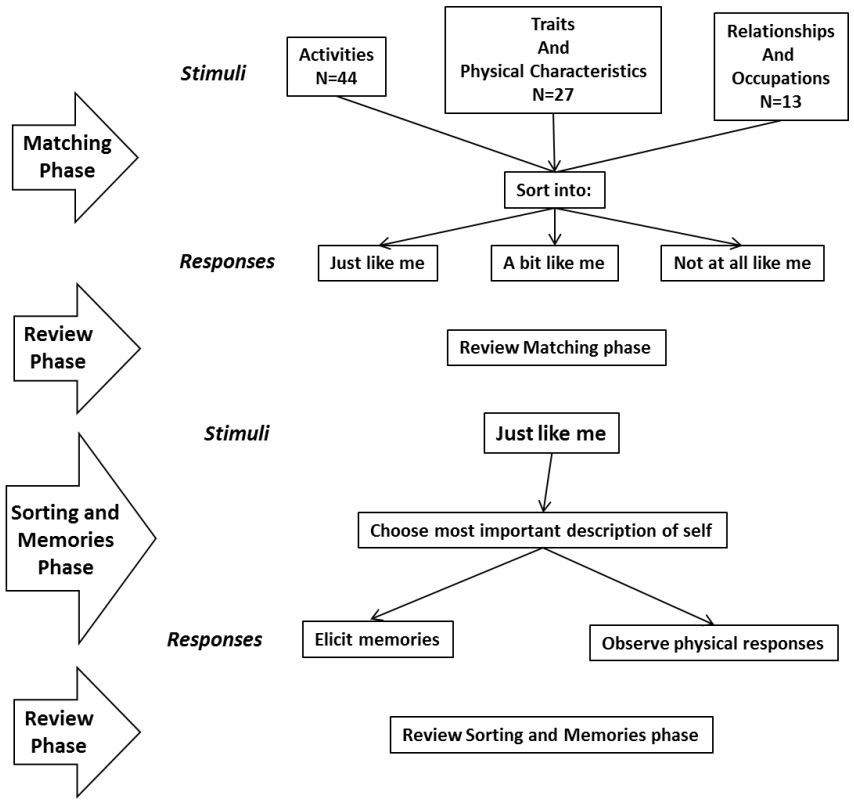


Figure 2: Administration of the Measure of Self

2.5.2 Matching Phase

If the participant agreed to being recorded the researcher will start the video recording. The researcher will begin the interview by placing the first set of stimuli on the table next to the participant. The three response cards will be in front of the participant. The researcher will hand the participant the stimuli one at a time and read from the instruction sheet: *"I am going to show you a picture. Do you think this picture is like you? Can you place it in front of the card that describes it best: 'Just like me', 'A bit like me', or 'Not at all like me'?"*

The researcher will allow time for the participant to think about his or her response, and to put the item on the table before giving him or her the next image. The researcher will give prompts if necessary to help the participant make a choice, such as *"Can you think of an occasion when you did this/were like this?* and if so, *"was it just like you or a bit like you?*

If a participant is unsure about the image on the front of the stimulus, the researcher will turn the stimulus over to show four more related images. If a participant is unable to place the stimulus in front of a response card but is showing indications (see Table 1) of how much like him or her the stimulus is, the researcher will place the stimulus in front of the relevant response card, and ask the participant if this is correct. The researcher will observe the participant to check that this is the correct position, for example nodding or smiling. If the participant is still unsure the researcher will put the stimulus to one side and categorise it as "Do not know". Video recordings will enable the gestures and facial expressions of the participants to be observed after the interviews. Gestures and expressions that appear to confirm choices (i.e. 'indicators of engagement', see Table 1), or indicate "Do not know" (i.e. 'neutral indicators') will be noted and inform the observational coding framework.

The procedure will continue until all the stimuli in the first set have been considered; the procedure will be repeated for the remaining sets. It is estimated that this phase will take approximately 32 minutes in total.

2.5.3 Review of Matching Phase

This review phase will identify aspects of the Measure of Self that need refinement by asking participants the following questions:

- *In the task we have just completed did you think the instructions were easy to understand?*
- *How well did you think the pictures matched the written statements?*
- *Was it easier to look at one picture or four pictures?*

It is estimated that these questions will take approximately 5 minutes to complete. Participants who cannot respond verbally will be asked how they feel at that moment, and the researcher will show them images of people looking puzzled, happy, or sad which the participant can point to. Video recordings will also enable the gestures and facial expressions of the participants to be observed after the interviews to aid interpretation of the review phase.

2.5.4. Sorting and Memory Phase

The self-descriptions that a person chooses as being most important for his or her self are associated with autobiographical memories that are more easily remembered (Rathbone & Moulin, 2014), therefore the Measure of Self will aim to elicit a narrative account associated with one stimulus that participants select as being most important for them. This will be accomplished by the methods described below.

When the participant is ready to continue the researcher will take all stimuli chosen as "Just like me". The researcher will give the participant two stimuli from the top of the "Just like me" pile and ask him/her to choose which one is most like him/her. If the participant is unsure how to choose between the two the researcher will ask questions depending on which set (activities, traits etc.) the stimuli are part of. Either *"If you had to choose between one of these activities which one would you like to do the most?* or *"Which of these describes you the best?*

The researcher will keep hold of the stimulus that the participant chooses as most like him/her and put the discarded stimulus to one side. The researcher will take the next stimulus from the "Just like me" pile and again ask the participant to choose between the two stimuli that the researcher is holding. The 'most like' stimulus will again be retained and the discarded one put to one side. This procedure will continue until all the "Just like me" stimuli have been studied and a single stimulus remains that will be considered to be the most important self-description. If the participant did not choose any "Just like me" stimuli, the "A bit like me" stimuli will be used. If the participant has not been able to complete this sorting phase, the researcher will finish the interview (see section 2.5.7 below).

When the most important stimulus has been chosen the researcher will read questions relevant to the stimulus to act as prompts, with reference to the Autobiographical Memory Interview (Kopelman et al, 1989):

- *Please can you look at this picture again? Does this picture bring back any memories for you?*
- *Can you tell me if it makes you think of a person, such as a relative, friend or someone you worked with?*
- *Does it make you think of a specific place, such as your home, school or place of work?*
- *Does it remind you of something that happened to you or something that you did?*

If the participant is unable to describe memories verbally, the researcher will show him or her more pictures connected with the topic of the chosen stimulus and allow the participant to respond to the pictures as they wish (see Appendix III). The ways that the participant responds will be

observed and noted after the interview by looking at the video recordings in order to inform the observational coding framework. It is estimated that this phase will take up to 10 minutes to complete.

2.5.5 Review of Sorting and Memory Phase

This review phase will again identify aspects of the Measure of Self that need refinement; participants will be asked the following questions:

- *What did you think about choosing between pictures two at a time?*
- *Did the pictures you chose help to bring back memories?*
- *Did the questions I asked help to bring back memories?*

It is estimated that this phase will take up to 5 minutes to complete. Participants who are unable to respond verbally will again be asked how they are feeling at that moment and be shown the pictures of peoples' faces to point to.

2.5.6 Recording participants' responses

Responses will be written on answer sheets that are identified by participants' ID numbers only (see Appendix VI). These will consist of two sets of tables relating to the Matching Phase and the Sorting and Memory Phase. There will be answer sheets for each of the three sets of stimuli presented during the Matching phase, and each sheet will comprise five columns headed: 'Just like me', 'A bit like me', 'Not at all like me', 'Don't know' and 'Review questions/comments'. A record of each stimulus chosen will be written in the relevant column, for example 'mother' in the 'just like me' column. Answers to questions asked during the review phase will be written in the 'comments' column.

The answer sheet for the Sorting and Memory Phase will comprise three columns headed 'Details of memory', 'Prompts' and 'Review questions/comments'. Descriptions or verbalisations expressed by participants will be written in the 'Details' column as accurately as possible, including gestures and facial expressions when these are observed by the researcher. These descriptions can be augmented when viewing video recordings. Recording the number and types of prompts given by the researcher will provide additional information for the Review Phase questions. If a participant talks quickly making it difficult for the researcher to write down all details of a memory the researcher will aim to note features of the memory that are indicative of episodicity, e.g. specific time and place. This process will be simplified for future studies because the coding framework that this study aims to develop will be used. The Episodicity/level of interest score (see Sections 3.4 to 3.6 below) will also be recorded on the 'Sorting and Memory' answer sheet. If a participant talks about a specific person who is identified by name, or a place that identifies the participant, the names of people or places will be noted and changed when data is recorded for analysis or when written in a report.

2.5.7 Finishing the interview and debriefing

It is envisaged that the full interview will last approximately 60 minutes and can be spread over two days if any participants prefer to do this. It is estimated that the collection of background information will take up to 15 minutes, and will be arranged for a later day if the participant wishes. The researcher will spend a few minutes at the end of the interview talking to and thanking the participant, and encourage him or her to ask questions if he or she wishes. The researcher will also ask the participants if they are still happy for the video recording to be retained. If not, the researcher will delete the recording immediately.

3. Scoring the Measure of Self

This study will evaluate the procedures for performing the Measure of Self, refine the numbers of stimuli and ensure that methods of scoring are feasible. At this stage the Measure of Self will yield scores relating to:

- Strength, complexity and quality of self (with reference to Addis & Tippet, 2004; Kuhn & McPartland 1954; Rathbone & Moulin, 2014)

- Episodicity Score for memories recalled by participants without verbal impairment (with reference to Kopelman et al, 1989)
- Level of Interest scoring framework for participants with verbal impairment (with reference to Klippi, 2015; Hyden & Peolsson, 2002; Mayhew et al, 2001)

3.1 Strength of Self

Strength of self will be measured by the total numbers of "Just like me", "Not at all like me" and "Do not know" responses across the whole measure of self. A greater number of definite responses (i.e. 'just like me' and 'not at all like me') suggests a strong sense of self; a higher number of "Do not know" responses suggests a weaker sense of self. The maximum score for strength of self is 84.

3.2 Complexity of Self

Complexity of self will be indicated by the number of subsets within each category of response ("Just like me" etc.). A more complex sense of self is indicated when a higher number of subsets are represented in "Just like me" and "Not at all like me" categories. A weaker sense of self is indicated by a greater number subsets represented in "A bit like me" responses. Scores will be: "Just like me" = 0 to 9; "A bit like me" = 0 to 9; "Not at all like me" = 0 to 9.

3.3. Quality of Self

The quality of self is related to the concrete and abstract nature of the stimuli; concrete statements refer to statuses and classes that are well defined and commonly understood such as 'husband', 'gardener' and 'teacher'. Abstract statements typically include references to attitudes and traits such as 'happy', 'clever' and 'thin'. Abstract statements are considered to require reflective thinking (Gallagher, 2000) and suggest a higher quality sense of self than concrete statements that come to mind quickly. The stimuli will comprise 43 concrete statements and 41 abstract statements; quality of self will be specified by calculating the proportions of concrete and abstract statements chosen as "Just like me" which will be out of 43 and 41 respectively.

3.4. Episodicity

When a participant talks about things that he or she remembers related to the stimulus chosen as being most important the researcher will record these in writing as accurately as possible. These memories will be scored according to the Episodicity Rating Scale (Kopelman et al, 1998) which rates the descriptive richness of the memories in terms of specificity of time and place.

Each account will be given a score ranging from 0 to 3, all the examples below relate to participants' first jobs:

0: A factual memory or statement, no personal details. *Example*: *"I worked at a shorthand typing college. It was very well run."*

1: A vague personal memory, no specific details. *Example: "I used to do a lot of paperwork. I thought it was boring."*

2: A personal memory but generalised rather than specific in time and place. *Example: "I played a lot of cricket for the works' team. I scored a century one year. We used to travel to places in London"*

3: A detailed memory occurring at a specified time and place, or with specific people. *Example: "We had a day out in London in one of the hotels. They took us by car from Peckham about 6.00 pm to a big hotel in central London. There was a dinner and a big speech. I sat next to a friend called Nellie. I was aged 18 at the time. We came home at 3.00 in the morning."*

Total scores for each participant will range from 0 to 3.

3.5 Observational Measures

For participants who have verbal impairment, observational measures will be used to rate their level of interest in the stimuli. These measures will be achieved by observing the facial expressions

and physical gestures that people use to enhance the meaning of conversations. These can be described as embodied behaviours, and have been shown to be retained by people with dementia who have difficulty expressing themselves verbally (Kontos, 2004), e.g. pointing (Klippi, 2015) and direction of gaze (Hyden & Peolsson, 2002). Studies have also shown that people with advanced dementia are able to express a range of emotions, such as furrowing of the brow (bewilderment), fidgeting (anxiety), exasperated voice tone (frustration) as well as smiling and laughter to display happiness (Mayhew et al, 2001). Thus, there is a wide variety of embodied behaviours that will be looked for and noted during the interviews in order to develop a coding framework equivalent to "just like me", "a bit like me" and "not at all like me". Table 1 lists examples of behaviours that may be observed; it is envisaged that this list will be extended after observing participants. Indicators of engagement suggest interest in the item; neutral indicators suggest lack of interest.

Table 1: Examples of observable behaviours

Indicators of engagement	Neutral Indicators
Smiling	Remaining still or silent
Nodding or shaking head	Fidgeting
Pointing (e.g. at self, part of the body, part of image)	Exasperated tone of voice
Looking at image	Hand movements unrelated to content of the item
Laughing	Wanting to move on to next item
Movements corresponding with activity shown	
Singing or humming	
Furrowing of brow	

3.6 Level of Interest

The researcher will note the reactions of participants during the interviews, and video recordings will be viewed afterwards to analyse behaviours in more detail. Analysis of gestures such as pointing, direction of gaze, fidgeting, smiling etc. (see Table 1) will be used to produce a 4-point scale, developed from the observational coding framework (see section 3.5 above). A possible scale would be:

0: No interest shown

1: Looking at pictures, showing interest but no signs of recognition.

2: Looking at pictures, nodding, but no movements or sounds related to the images.

3: Looking at pictures, pointing or touching them and own body, smiling, acting out movements related to the images.

Total scores for each participant will range from 0 to 3

3.7 Priority of measures for completion

The Measure of Self will be presented in the following order:

The 'Traits and Physical Characteristics' section (consisting of 27 images) will be presented first. If a participant is finding the task difficult, or is slow to choose responses, the 'Relationships and Occupations' section (13 images) will be presented next, and the 'Activities' section (44 images) along with the sorting and memory phase will be completed during a second appointment, if the participant is willing, when she/he is less fatigued. Alternatively, these final stages will be omitted.

This should allow full data collection regarding 2/3 aspects of self and at least partial collection of data regarding all 3 aspects and autobiographical memory. This will permit an assessment of how feasible it is to administer the whole test and also yield sufficient information to determine if informative outcomes can be achieved with a reduced set of stimuli.

Measures that will be used to gain background information (GDS4 and ACE-III) will be administered on a convenient day for the participant after the Measure of Self has been completed.

3.8 How findings of this study will be used

The purpose of this study is to ensure that the Measure of Self is suitable for the purpose of measuring sense of self in people with dementia and that the data provided by participants can be scored as presented above. Therefore. the aims of the study are:

i. Refinement of number of items in the measure.
ii. Clarification of numbers of images shown for each item.
iii. Confirm understanding of instructions by participants.
iv. Confirm effectiveness of the three 'like me' responses.
v. Establish a scoring framework for participants with limited vocabulary.

These will be achieved by:

i. Items that produce null responses, or are considered inappropriate or difficult to choose responses will be removed from the measure.

ii +iii. Clarification of numbers of images and understanding of instructions will be investigated by questioning the participants during the two review phases. This will be augmented by watching video recordings after the interviews to observe the physical gestures of the participants.

iv. The effectiveness of the three responses (just like me, a bit like me, not like me) will be assessed by calculating the frequencies of each response to determine if there is a good spread for each category. If there is significant weighting towards one of the responses an alternative method of responding will be considered.

v. A scoring framework will be established by observing and noting gestures and facial expressions during the interviews and by looking at video recordings afterwards. A starting point for this framework will be to clarify positive and negative indicators related to the three response categories.

4. Ethical Considerations and Consent Procedures

4.1 Informed consent

This project will recruit participants who have been diagnosed with dementia and therefore the consent process will ensure that only participants who have capacity to consent will be included. It is essential to obtain informed consent before any person takes part in a research study, and this issue is especially important for people with dementia who may have communication difficulties that impair their ability to express any concerns about taking part.

All prospective participants will be given an information sheet describing the study. This information will have two versions; one consisting of written words only, the other will have pictures and fewer words. This latter version will be shown to participants who have difficulty with reading. However, the researcher will assist participants, if required, with both versions of the forms. As well as details of the study, and what is required of participants, ethical requirements such as confidentiality, right to withdraw and who to ask for further information will be discussed. Prospective participants will be able to keep the information sheet and take it away to help them consider whether or not to take part in the study. They will be given up to 48 hours to decide whether or not to take part, take longer if they wish, or decide straight away whether or not to take part. They will be encouraged to talk about the study with family or friends before making the decision. The researcher will contact the prospective participants again after 48 hours, or later if they wish, to enable them to ask questions about the study. During the second visit the researcher will review participants' capacity to consent and withdraw. If a participant wishes to withdraw any information collected up to this point will be destroyed.

4.2 Right to withdraw

An important feature of the consent process is that the participant has the freedom to continue or withdraw from the study, and it must be clear that the researcher does not exert any influence

over the participants to remain in the study. The researcher will ensure the continued welfare of the participants, and will always be aware of verbal and nonverbal behaviour which indicates that a participant may wish to withdraw.

4.3. Confidentiality

Confidentiality requires that a participant cannot be identified by any means in the data that is collected by the researcher. No participant will be identified by name or association. Each participant will be assigned a unique identification code to ensure anonymity. All paper-based research records will be stored in locked filing cabinets at the University of Bradford which only authorised staff can access. Electronic data records will be stored on password protected computers at the University of Bradford, for up to 5 years. Only minimum identifiable data needed for administration purposes will be collected or recorded and only the student and principal supervisors will have access to identifiable data.

4.4. Risks and benefits

There should be minimal risk for participants. However, it is possible that participants may remember unhappy events and become distressed. If this happens the researcher will ask the participant if they would prefer to move on to another question, or take a short break. Also, if a participant says he or she feels tired, or show signs of fatigue, the researcher will ask if they would like to take a break. After the break the participant will be asked if he or she would like to continue, or prefer to stop and complete the interview later that day or on another day, or withdraw from the study. If this is the case they will be allowed to do so, and need not give reasons for this.

There are no direct benefits to participants but there may be satisfaction in feeling that they are contributing to a research study that has the potential to help others in the future.

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Appendix XII: Notification of IRAS Approval

Yorkshire & The Humber - Leeds West Research Ethics Committee
Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT
Telephone: 0207 104 8086

01 March 2017
Mrs Rosemary Bradley
Faculty of Health Studies
University of Bradford
Richmond Road
BD7 1DP

Dear Mrs Bradley

Study title: An Objective Measure of Self for People Living With Dementia

REC reference: 16/YH/0473
IRAS project ID: 190354

Thank you for your letter of 15th February, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

The committee did not approve this research project for the purposes of the Mental Capacity Act 2005. The research may not be carried out on, or in relation to, a person who lacks capacity to consent to taking part in the project.

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr Sheila E. Fisher

Chair

Appendix XIII: Pilot Study Poster/Leaflet

UNIVERSITY of BRADFORD

Introducing a new study…

The Bradley Measure of Self

Who are we looking for?

- **We are looking for volunteers who have problems with their memory and would be willing to talk to me about themselves.**

What would you have to do?

- **You would be invited to take part in a study that is developing a new measure of 'self'**
- **You will be asked to answer some questions about how you describe yourself.**
- **This will take the form of an interview that will last about an hour.**
- **I will visit you in your home or somewhere that is familiar to you to carry out the interview.**

What is the study about?

People with memory problems may have difficulty recalling recent and past events which can affect a person's sense of self and identity. Research has shown that good quality care can stop this happening. The purpose of my study is to develop a measure of self that can be used by researchers in the future who are carrying out studies about care.

If you would like to take part in the study please tell the person who gave you this leaflet, or contact me,

Rosemary Bradley, at the University of Bradford:
Tel: 01274 236377 Email: R.J.Bradley@student.bradford.ac.uk

Appendix XIV: Pilot Study Participant Information Sheets Text and Pictorial Versions

UNIVERSITY of BRADFORD

PhD Research Study: The Measure of Self

Participant Information Sheet

Who is performing this study?
My name is Rosemary Bradley and I am studying for a PhD at the University of Bradford

What is my study about?
People with memory problems often have difficulties in recalling recent and past events. This can affect a person's sense of self or identity. Other people often assume that those who have memory problems lose their sense of self and identity as their memory gets worse. However, research has shown that good quality care that supports identity can stop this happening. One challenge for researchers is that we do not currently have any ways to measure self or identity in people with memory problems.

The purpose of my study is to develop a measure of self for people with memory problems. I hope this will be used by researchers in the future when carrying out studies about care.

Why am I inviting you to take part?
I am seeking people with memory problems who would be willing to talk with me about themselves. I understand that you have memory problems and may be willing to take part. My interviews will help me decide what questions should be included in the measure of self, and the best ways of asking them.

What will I ask you to do?
I will show you some pictures that will help you to tell me about yourself, such as:

- How you describe yourself.
- Activities you do now and things you used to do.
- Things that you remember doing with other people.

I will also ask you to tell me what you thought when you were answering my questions. This will help me to know if I am asking the right sort of things. There will be no right or wrong answers. I am only interested in what you

think about the questions, and I hope that you will find the interview interesting and enjoyable. Finally, I will ask you some short questions about your mood and your memory.

Will the interviews be video recorded?
Yes, if you are agreeable, but this is only to remind me of what we talked about and see if you made any movements that may have helped you remember things. I will ask you before we start if you are happy for me to record. I will not mind if you say 'no'. The video recording will be stored safely. You will not be identified by name on the recording. I will also ask you at the end if you are still happy for me to keep the recording. If not, I will delete it straight away.

Will what you say be confidential?
Yes. I will write down what you say but I will not use your name. I will always use a special code instead of your name. If you say anything that you would prefer me not to write down just tell me and I will not do so. If I have already written it down I will make sure it is taken off the answer sheet. The only other people who will see your answers are my PhD supervisors. I will only keep the information until I have finished writing about my study which will be no more than 5 years from now. After then all the information you have given me will be destroyed.

I may use some of the things you tell me in my reports, but I will not use your name, and will change any details that might mean other people would recognise who said them.

How long will the interview take?
Probably about 60 minutes; and we can take breaks if you get tired or finish the interview on another day.

Are there any risks in taking part?
I do not expect there to be any risks. If you think of anything that upsets you when I am asking you questions you can take a break and we can decide if you would like to continue. If you experience any problems, or feel uncomfortable at any time, tell me and I will stop immediately. You can stop at any time and do not have to explain why. If you do not want your data to be used it will be deleted.

Will travel expenses be reimbursed?
Yes, if you incur any travel expenses by taking part in this study they will be reimbursed in full.

What should you do if you would like to help with my study?
You do not need to decide straight away. Please take time to think about it, and talk it over family or friends if you wish. I will come back to see you in a

day or so to find out if you would like to take part. You can keep this sheet as a reminder, and ask me some more questions if you have any.

If you decide to take part I will ask you to sign a consent form. I will explain what the consent form means and make sure you are happy to sign it. I will then arrange a time to see you again in the next day or so to ask you my questions.

What will happen when I take part?
We will find a quiet place to sit together. When you are ready to start I will ask you some questions about your memory and things that you do during the day. Then I will ask you about yourself. I will also ask you to tell me what you are thinking about as you answer my questions.

When we have finished we can talk a little longer about the measure, and you will be able to ask me questions about my study if you want to.

What will happen if I lose capacity to consent to continue?
The data I have collected up to the point of loss of capacity will be destroyed.

What will happen to the information you give me?
I will use it to decide what questions will be in the next version of the Measure of Self and how I should ask them. I will then ask some more people to try out the new version that you have helped me to write.

I will write a report that will form part of my PhD thesis. I will talk about my results at conferences and with other researchers and people with dementia.

If you would like more information, please contact me at the University of Bradford (or ask someone else to do so on your behalf)

Rosemary Bradley
Tel: 01274 236377
Email: R.J.Bradley@student.bradford.ac.uk

Thank you for reading this information sheet.

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Ms Tamsin Holt
Title: Head of Research Support
Email: nhs-ethics@bradford.ac.uk Telephone: 01274 2360000

Participant Information Sheet
PhD Study: The Measure of Self

Hello! My name is Rosemary Bradley

I am a PhD Student working at Bradford University.

I am carrying out a study about sense of self in people who have memory problems.

I will be performing the study myself but

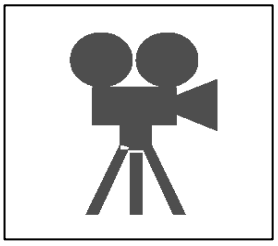
I would like to ask you some questions about your memory and mood, and how you describe yourself.

I will show you some pictures to help you remember things.

I will write down what you tell me but no one else will know what you have told me except my supervisors.

I will ask these questions in a place that is comfortable and familiar to you. If you have to pay travel expenses these will be reimbursed in full.

You will be able to have a rest if you like



I will film us both when I am asking questions, but you can tell me if you would rather not be filmed.
I will not show the film to anyone else except my supervisors.

If you would like to help me with my study I will visit you again.

I will ask you to sign a consent form

I will help you do this and you can have someone else with you if you like

I will fix a date and time to visit you again to ask you the questions about yourself.

I will also ask you to tell me what you are thinking when you answer the questions.

Do not worry if you cannot answer some of the questions. There are no right or wrong answers.

This should take about one hour.

If you change your mind at any time you can tell me to stop.

If you feel unwell or uncomfortable at any time you can tell me to stop.

If you would like to know more about the study you can ask someone to contact me at Bradford University:

Rosemary Bradley

Tel: 01274 236377

Email: R.J.Bradley@student.bradford.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Ms Tamsin Holt

Title: Head of Research Support

Email: nhs-ethics@bradford.ac.uk Telephone: 01274 2360000

Appendix XV: Pilot Study Consent Form

PhD Study: The Measure of Self

Participant Consent Form

Please initial box

I confirm that I have read and understand the information sheet for the above study and have had the chance to ask questions. ☐

I understand the purpose of the study and know what my involvement will be. I do not need any more information now but know I am free to request it at any time. ☐

I understand that it is my decision to take part or not and that I am free to withdraw at any time without giving any reason. ☐

I understand that I will not be identified by name. ☐

I understand that a video will be used as part of this study. ☐

I agree to video recordings being made on the understanding that the material will be retained securely and only be used for the current study. ☐

Should my ability to make decisions change during the study period I would like ……..to be consulted about whether they think I would still be happy to take part in the study. ☐

I agree to take part in the study. ☐

Signed…… Date……

Name (in block letters) ……

Researcher

I have explained the study to the above named participant and he/she has indicated his/her willingness to participate.

Signed…… Date……

Name (in block letters) ……

FAST SCALE ADMINISTRATION

The FAST scale is a functional scale designed to evaluate patients at the more moderate-severe stages of dementia when the MMSE no longer can reflect changes in a meaningful clinical way. In the early stages the patient may be able to participate in the FAST administration but usually the information should be collected from a caregiver or, in the case of nursing home care, the nursing home staff.

The FAST scale has seven stages:

1 which is normal adult
2 which is normal older adult
3 which is early dementia
4 which is mild dementia
5 which is moderate dementia
6 which is moderately severe dementia
7 which is severe dementia

FAST Functional Milestones.
FAST stage 1 is the normal adult with no cognitive decline. FAST stage 2 is the normal older adult with very mild memory loss. Stage 3 is early dementia. Here memory loss becomes apparent to co-workers and family. The patient may be unable to remember names of persons just introduced to them. Stage 4 is mild dementia. Persons in this stage may have difficulty with finances, counting money, and travel to new locations. Memory loss increases. The person's knowledge of current and recent events decreases. Stage 5 is moderate dementia. In this stage, the person needs more help to survive. They do not need assistance with toileting or eating, but do need help choosing clothing. The person displays increased difficulty with serial subtraction. The patient may not know the date and year or where they live. However, they do know who they are and the names of their family and friends. Stage 6 is moderately severe dementia. The person may begin to forget the names of family members or friends. The person requires more assistance with activities of daily living, such as bathing, toileting, and eating. Patients in this stage may develop delusions, hallucinations, or obsessions. Patients show increased anxiety and may become violent. The person in this stage begins to sleep during the day and stay awake at night. Stage 7 is severe dementia. In this stage, all speech is lost. Patients lose urinary and bowel control. They lose the ability to walk. Most become bedridden and die of sepsis or pneumonia.

Functional Assessment Staging of Alzheimer's Disease. (FAST)©

STAGE	SKILL LEVEL

1. No difficulties, either subjectively or objectively
2. Complains of forgetting location of objects. Subjective word finding difficulties.
3. Decreased job function evident to co-workers: difficulty in travelling to new locations. Decreased organizational capacity. *
4. Decreased ability to perform complex tasks (e.g. planning dinner for guests), handling personal finances (forgetting to pay bills), difficulty marketing, etc.
5. Requires assistance in choosing proper clothing to wear for day, season, occasion.

6a. Difficulty putting clothing on properly without assistance.

6b. Unable to bathe properly; (e.g., difficulty adjusting bath water temperature) occasionally or more frequently over the past weeks. *

6c. Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks. *

6d. Urinary incontinence, occasional or more frequent.

6e. Faecal incontinence, occasional or more frequently over the past week.

7a. Ability to speak limited to approximately a half dozen words or fewer, in the course of an average day or in the course of an intensive interview.

7b. Speech ability limited to the use of a single intelligible word on an average day or in the course of an interview (the person may repeat the word over and over).

7c. Ambulatory ability lost (cannot work without personal assistance)

7d. Ability to sit up without assistance lost (e.g., the individual will fall over if there is no lateral rests [arms] on the chair).

7e. Loss of ability to smile.

STAGE: _____

*Scored primarily on the basis of information obtained from a knowledgeable informant and/or caregiver.

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Appendix XVII: GDS4 Form

Participant ID: _____

MOOD QUESTIONNAIRE			
Questions	**Circle one answer**		**Score**
Are you basically satisfied with your life?	**Yes**	**NO**	
Do you feel that your life is empty?	**YES**	**no**	
Are you afraid that something bad is going to happen to you?	**YES**	**no**	
Do you feel happy most of the time?	**Yes**	**NO**	
		Total	

To Score: If answer chosen is in CAPITALS then give 1 mark otherwise 0

Results:

0 = Not Depressed

1 = Uncertain

2 to 4 = Depressed

Appendix XVIII: ACE-III Form

Page 1

ADDENBROOKE'S COGNITIVE EXAMINATION – ACE-III
English Version A (2012)

Name: Date of Birth: Hospital No. or Address:	Date of testing: ___/___/___ Tester's name: _____ Age at leaving full-time education: _____ Occupation: _____ Handedness: _____

ATTENTION

➢ Ask: What is the	Day _____	Date _____	Month _____	Year _____	Season _____	**Attention** [Score 0-5] ☐
➢ Ask: Which	No./Floor _____	Street/Hospital _____	Town _____	County _____	Country _____	**Attention** [Score 0-5] ☐

ATTENTION

➢ Tell: "I'm going to give you three words and I'd like you to repeat them after me: lemon, key and ball." After subject repeats, say "Try to remember them because I'm going to ask you later". ➢ Score *only* the first trial (repeat 3 times if necessary). ➢ Register number of trials: _____	**Attention** [Score 0-3] ☐

ATTENTION

➢ Ask the subject: "Could you take 7 away from 100? I'd like you to keep taking 7 away from each new number until I tell you to stop." ➢ If subject makes a mistake, do not stop them. Let the subject carry on and check subsequent answers (e.g., 93, 84, 77, 70, 63 – score 4). ➢ Stop after five subtractions (93, 86, 79, 72, 65): ___ ___ ___ ___ ___	**Attention** [Score 0-5] ☐

MEMORY

➢ Ask: 'Which 3 words did I ask you to repeat and remember?' _____ _____ _____	**Memory** [Score 0-3] ☐

FLUENCY

➢ **Letters** Say: "I'm going to give you a letter of the alphabet and I'd like you to generate as many words as you can beginning with that letter, but not names of people or places. For example, if I give you the letter "C", you could give me words like "cat, cry, clock" and so on. But, you can't give me words like Catherine or Canada. Do you understand? Are you ready? You have one minute. The letter I want you to use is the letter "P".	**Fluency** [Score 0 – 7] ☐

				≥ 18	7
				14-17	6
				11-13	5
				8-10	4
				6-7	3
				4-5	2
				2-3	1
				0-1	0
				total	correct

➢ **Animals** Say: "Now can you name as many animals as possible. It can begin with any letter."	**Fluency** [Score 0 – 7] ☐

				≥ 22	7
				17-21	6
				14-16	5
				11-13	4
				9-10	3
				7-8	2
				5-6	1
				<5	0
				total	correct

ACE-III Page 2

MEMORY

➢ Tell: "I'm going to give you a name and address and I'd like you to repeat the name and address after me. So you have a chance to learn, we'll be doing that 3 times. I'll ask you the name and address later."

Score only the third trial.

Memory [Score 0 – 7] ☐

	1st Trial	*2nd Trial*	*3rd Trial*
Harry Barnes 73 Orchard Close Kingsbridge Devon			

MEMORY

➢ Name of the current Prime Minister.....
➢ Name of the woman who was Prime Minister .....
➢ Name of the USA president.....
➢ Name of the USA president who was assassinated in the 1960s.....

Memory [Score 0 – 4] ☐

LANGUAGE

➢ Place a pencil and a piece of paper in front of the subject. As a practice trial, ask the subject to "**Pick up the pencil and then the paper.**" If incorrect, score 0 and do not continue further.

➢ If the subject is correct on the practice trial, continue with the following three commands below.
- Ask the subject to "**Place the paper on top of the pencil**"
- Ask the subject to "**Pick up the pencil but not the paper**"
- Ask the subject to "**Pass me the pencil after touching the paper**"

Note: Place the pencil and paper in front of the subject before each command.

Language [Score 0-3] ☐

LANGUAGE

➢ Ask the subject to write two (or more) complete sentences about his/her last holiday/weekend/Christmas. Write in complete sentences and do not use abbreviations. Give 1 point if there are two (or more) complete sentences about the one topic; and give another 1 point if grammar and spelling are correct.

Language [Score 0-2] ☐

LANGUAGE

➢ Ask the subject to repeat: **'caterpillar'; 'eccentricity; 'unintelligible'; 'statistician'**
Score 2 if all are correct; score 1 if 3 are correct; and score 0 if 2 or less are correct.

Language [Score 0-2] ☐

ACE-III Page 3

LANGUAGE

- Ask the subject to repeat: **'All that glitters is not gold'**

Language [Score 0-1] ☐

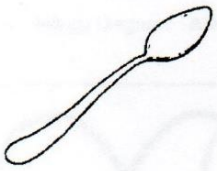
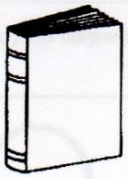
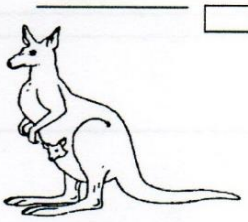
- Ask the subject to repeat: **'A stitch in time saves nine'**

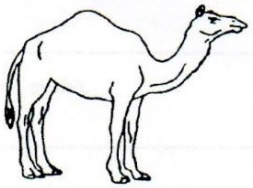
Language [Score 0-1] ☐

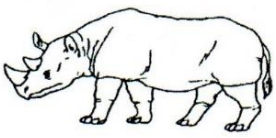
LANGUAGE

- Ask the subject to name the following pictures:

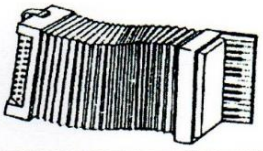
Language [Score 0-12] ☐







LANGUAGE

- Using the pictures above, ask the subject to:
  - Point to the one which is associated with the monarchy .....
  - Point to the one which is a marsupial .....
  - Point to the one which is found in the Antarctic .....
  - Point to the one which has a nautical connection .....

Language [Score 0-4] ☐

Updated 20/11/2012

ACE-III Page 4

LANGUAGE

➢ Ask the subject to read the following words: (Score 1 only if all correct)

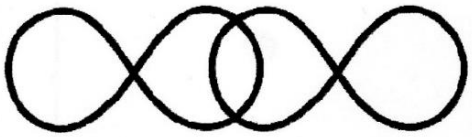
Language [Score 0-1] ☐

sew
pint
soot
dough
height

VISUOSPATIAL ABILITIES

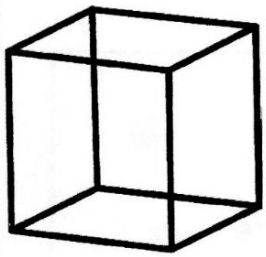
➢ Infinity Diagram: Ask the subject to copy this diagram

Visuospatial [Score 0-1] ☐



➢ Wire cube: Ask the subject to copy this drawing (for scoring, see instructions guide).

Visuospatial [Score 0-2] ☐



➢ Clock: Ask the subject to draw a clock face with numbers and the hands at ten past five. (For scoring see instruction guide: circle = 1, numbers = 2, hands = 2 if all correct).

Visuospatial [Score 0-5] ☐

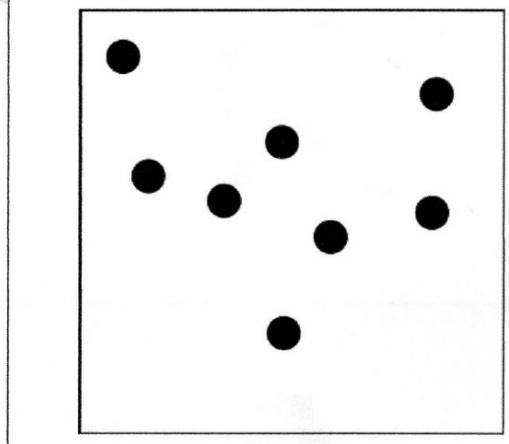
Updated 20/11/2012

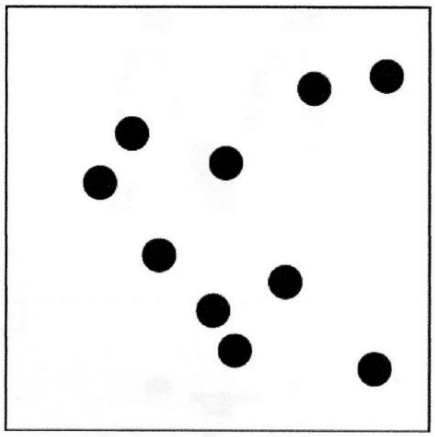
ACE-III Page 5

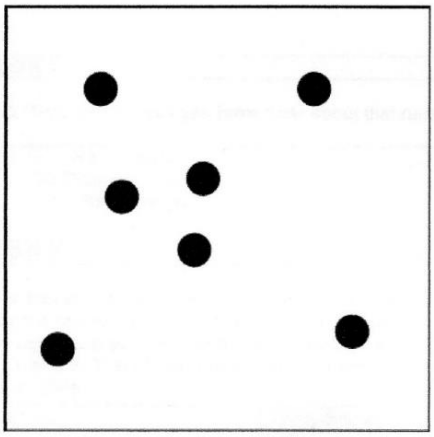
VISUOSPATIAL ABILITIES

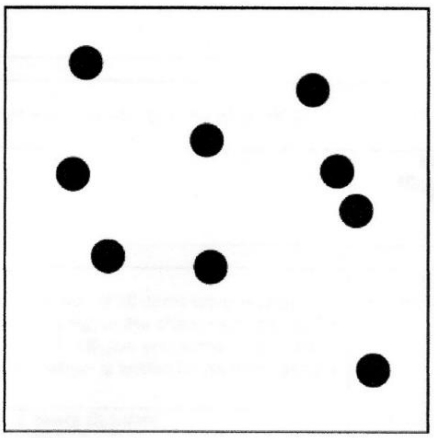
➢ Ask the subject to count the dots **without** pointing to them

Visuospatial
[Score 0-4]









Updated 20/11/2012

ACE- III Page 6

MEMORY

- Tell: "I'm going to give you a name and address and I'd like you to repeat the name and address after me. So you have a chance to learn, we'll be doing that 3 times. I'll ask you the name and address later."

Score only the third trial.

Memory [Score 0 – 7] ☐

	1st Trial	*2nd Trial*	*3rd Trial*
Harry Barnes 73 Orchard Close Kingsbridge Devon			

MEMORY

- Name of the current Prime Minister.....
- Name of the woman who was Prime Minister .....
- Name of the USA president.....
- Name of the USA president who was assassinated in the 1960s.....

Memory [Score 0 – 4] ☐

LANGUAGE

- Place a pencil and a piece of paper in front of the subject. As a practice trial, ask the subject to "**Pick up the pencil and then the paper.**" If incorrect, score 0 and do not continue further.
- If the subject is correct on the practice trial, continue with the following three commands below.
  - Ask the subject to "**Place the paper on top of the pencil**"
  - Ask the subject to "**Pick up the pencil but not the paper**"
  - Ask the subject to "**Pass me the pencil after touching the paper**"

  Note: Place the pencil and paper in front of the subject before each command.

Language [Score 0-3] ☐

LANGUAGE

- Ask the subject to write two (or more) complete sentences about his/her last holiday/weekend/Christmas. Write in complete sentences and do not use abbreviations. Give 1 point if there are two (or more) complete sentences about the one topic; and give another 1 point if grammar and spelling are correct.

Language [Score 0-2] ☐

LANGUAGE

- Ask the subject to repeat: **'caterpillar'; 'eccentricity; 'unintelligible'; 'statistician'**

Score 2 if all are correct; score 1 if 3 are correct; and score 0 if 2 or less are correct.

Language [Score 0-2] ☐

Appendix XIX: Like Me Responses

Just like me

Cutting line_____

A bit like me

Cutting line_____

Not at all like me

Cutting line_____

Appendix XX: Administration Sheets (all studies)

Participant ID: _____

Answer Sheets: Matching Traits and Physical Characteristics

1. I am going to show you a picture. Do you think this picture is like you?
2. Can you place it in front of the card that describes it best: Just like me, a bit like me, or not at all like me.

Repeat Q2 five times (or more if participant continues to be unsure) at start of each set of stimuli.

If necessary, prompt with: **Would you say you are [read from stimulus], or Would you say being [??] is just like you, a bit like you or not at all like you?**
Show images on reverse of stimulus if participant is still unsure. Allow time for him/her to place the card him/herself.

Just like me	A bit like me	Not at all like me	Don't know/Comments

Participant ID: _____

Answer Sheets: Matching Relationships and Occupations

Relationships:

1. I am going to show you a picture. Do you think this picture is like you?

2. Can you place it in front of the card that describes it best: Just like me, a bit like me, or not at all like me.

Occupations:

1 I am going to show you some pictures of occupations and I would like to find out what types of work you identify most with, or is most meaningful to you.

2. Do you think this occupation is like you?

3. Can you place it in front of the card that describes it best: Just like me, a bit like me, or not at all like me.

Repeat Q2 five times and show images on reverse of stimulus if participant is still unsure. Allow time for him/her to place the card him/herself.

Just like me	A bit like me	Not at all like me	Don't know/Comments

Participant ID: _____

Answer Sheets: Matching Activities

1. I am going to show you a picture. Do you think this picture is like you?

2. Can you place it in front of the card that describes it best: Just like me, a bit like me, or not at all like me.

Repeat Q2 five times and show images on reverse of stimulus if participant is still unsure. Allow time for him/her to place the card him/herself.

Just like me	A bit like me	Not at all like me	Don't know/Comments

Participant ID: _____

Sorting and Memory Phase

Take one of the three sets of 'Just Like Me' stimuli. Show the participant two stimuli from the top of the pile. Ask the participant:

- **Please can you choose which one is most important to you?**

Prompts:

- **If you had to choose between one of these activities, which one would you like to do most?**
  Or:
- **Which of these describes you best?**

1. Keep hold of the stimulus chosen as 'most like' the participant. Take the next stimulus from the pile and ask the participant to again choose which one is most like him/her.

2. Continue until all the stimuli have been considered and one remains that is the 'most important' stimulus from the set.

3. Repeat for the two remaining sets of stimuli to give three 'most important' stimuli.

4. Ask the participant to choose between these in order to be left with one stimulus.

Participant ID: _____

Memory Phase

Give the 'most important' to the participant or place in front of him/her, then read:

- **Please can you look at this picture again. Can you tell me about a memory you have about being… [whatever the statement says]?**
- **Please try and tell me all the things you remember about it.**
- **Can you tell me a little more about that?** [Repeat up to three times until no more detail is given and record how many prompts were used.]

Details of memory	Prompts	Comments

Memory Rating: _____ **Details of pseudonyms and/or replacements_____**

Appendix XXI: Memory Transcripts

Pilot Study – Memory Transcripts

Episodicity Scores:
0: Factual memory or statement, no personal details
1: Vague personal memory but no contextual details. Generic events that occur over repeated time intervals. Events blend or fuse together.
2: Non-specific, general events forming narrative spanning more than 24 hours. Some contextual details such as who with, emotions, where it happened.
3: Specific, unique event lasting less than 24 hours. Contextual details as if reliving the event.

Note that some of the transcripts include conversations that continued after the study questions had been asked.

S102 = 3
Stimulus: I am a husband
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being a husband? Can you tell me all the things you remember about it?

P: Er… when we got married at, er, in church. What I can always remember about that, it was a summer…We got married in June and it were a lovely summer's day but it were freezing in church. I can always remember that. Absolutely freezing.

R: Can you tell me a little more about that?

P: Holidays together. We've always had…we've had some real holidays…yeh.

S103 = 0
Stimulus: I am honest
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being honest?

P: No.

R: Can you tell me all the things you remember about it?

P: Well, no, I can't think of anything.

R: If we said being happy, can you remember a time when you were very happy?

P: I'm trying to think….I'm always happy. I can't think of such….you know… Just life makes me happy…meeting new people.

[Recording stopped but participant was able to talk about working as a seamstress – sewing lace on lingerie.]

S104 = 2
Stimulus: I am a traveller
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being a traveller?

P: Yeh, well I went on holiday with a friend last year. The two of us went to Tenerife for a week. That was lovely.

R: Can you tell me all the things you remember about it?

P: Every day was lovely in a 5-star hotel, so it really was a fantastic holiday. I do go backwards and forwards to Germany.

R: Can you tell me a little more about that?

P: I've gone since I was small.

R: Did the pictures bring back memories?

P: Yes, they did. I don't really think about things I did when I was younger, like being in the Brownies and camping. It wasn't until you see something, then it brings back [points to head].

S105 = 1
Stimulus: I am a knitter
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being knitter? Can you tell me all the things you remember about it?

P: Er, yes, cardigans, jumpers, you know.

R: Would these be for yourself, or for your family?

P: Yes, f't family.

R: Any particular reason? Did you give one to anybody for a birthday present?

P: No, I used to knit for them if they used to bring me a pattern.

R: Can you remember going to buy any wool, or anything in particular? Was there a particular shop that you used to go to?

P: [indistinct] Mills.

R: Sorry, Urwin Mills?

P: No, Robin Mills.

R: What sort of knitting did you like to do?

P: I used to like….with twists and that.

R: Cable?

P: Cable, yeh. I don't think I was good at….I didn't have enough patience for Fairisle. All the different colours [mimes with her hands].

S107=1
Stimulus: I am a family person.
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being a family person? Can you tell me all the things you remember about it?

P: We started the family really…I was working…came home. First son, second son, third son.

R: Can you tell me all the things you remember about it?

P: We lost the youngest son.

Wife: was there anything that was more important with them?

R: Days out?

P: Yes, we do go on holidays with the family.

R: Do any holidays stand out….special, extra special?

P: Last years was a good one.

R: Can you remember…?

P: How many cruises? We've been on quite a few cruises.

S108 = 3
Stimulus: I am a steam enthusiast
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being a steam enthusiast? Can you tell me all the things you remember about it?

P: Going back a few years now aren't we? I met S [his wife] and she was going down with three girls to, er, down to Torquay wasn't it? Did I book on the train or come down with you? I booked on the same one and went down with them.

R: Can you tell me a little more about that?

P: One lad and four lasses…. must have been brilliant. I had a brilliant time. They looked after me well.

S109 = 3
Stimulus: I have good manners
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of having good manners? Can you tell me all the things you remember about it?

P: Well it brings back millions of memories 'cos I've met loads and loads of people and I've always been trying to be helpful and trying to be friendly. I met a lot of people who had no friends at all. So I always used to feel sympathetic to them and try to give out a little bit to enable them to enjoy….so I suppose I've enjoyed that as a major part of my life.

R: Can you tell me a little more about that?

P: Well you might find this bragging, but I remember going to a dinner, and, erm, I had to stand up and make a little speech. And I said, I can't remember the exact words, but it was something like "I just hope you've all enjoyed tonight as much as I have because I've seen all of you smiling, and heard all of you chatting, and it appears to me we've done it right. So I'm speaking on behalf of everybody who's trying to help put this event on, and I'd like to say thank you to everybody, and if anybody disagrees with me, will they come outside", because I want to be producing good manners all the time.

S110 = 3
Stimulus: I am a husband
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being a husband?

P: When we had our one and only child….and when we actually got married.

R: Can you tell me all the things you remember about it?

P: Just the fact that we did. Well…when you find out she's pregnant, until it actually happens you're not sure whether it's a girl or a boy…waiting to see what you are going to have, and when you do, you're blessed.

R: Can you tell me a little more about that? You felt blessed with having a son?

P: Well, yes, because my mother and father had died and all that, and I'd lived on my own, and I'd got to nearly 50…life seemed to be zeee [motions downward slant], then all of a sudden, things changed, and all that…yeh.

R: So you had a son when you were 50?

P: No, no, I'd be….yeh….contrived him before we actually got married.

R: You don't need to go into too many details.

P: What I'm saying…life had become a little bit uhhh [hand down] then all of a sudden…[hand up]…that's what I'm saying.

S111 = 1
Stimulus: I am punctual
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being punctual?

P: Erm., when I used to go to school or work, I were always punctual. You had to be. I can't ever remember being not punctual. It would have to be something very serious to not arrive on time.

R: Can you tell me all the things you remember about it?

P: I just used to wake up at the time I needed to.

R: Can you tell me a little more about that?

P: I was a poor sleeper so as soon as light was at the windows I'd be waking up, and obviously you've got the clock and things.

R: What times did you have to be ready for work or at work?

P: When I used to work, around 7 am.

R: What was it like in the winter when you had to go in the dark?

P: It was fine when I was driving a car, but when I was riding a motor bike in the winter it got more tricky.

Conversation continued about motor bikes, learning to drive and driving cars.

S112 = 1
Stimulus: I am religious

R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being a religious person? Can you tell me all the things you remember about it?

P: I can remember, erm, having to go up and read something in church.

R: Can you tell me a little more about being at church?

P: Harvest festivals.

S113 = 3
Stimulus: I am a cricket fan
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being a cricket fan?

P: I've been to a few [matches]. I was a member of Yorkshire for ages.

R: Can you tell me all the things you remember about it?

P: Yes, a test match against the West Indies, I can't tell you the er…. Clive Lloyd was the captain and I went up to him. Could he tell me, what did he think of Geoff Boycott? He said "In what way love?" So I said "Well, do you think he's a good er…?" He said "As a man I admire him, as a cricketer I can't [indistinct]". I said "If you haven't got him out by the time he's got 50, don't bother. He'll get 100, or get him s'en out". And he did that, if he'd got 100, he'd go on and get 150. He'd get 149 and as he's running for his 150 run he'll be run out.

R: Can you tell me a little more about Geoff Boycott? Have you ever met him?

P: Oh, a few times.

R: What did you think of him then, as a man?

P: Oh I liked him. And for umpires, Dickie Bird. Dickie was a really good umpire, and er, one day I said "Mr. Bird, why don't you stick your finger up for [indistinct]? He said "Darling, I can't do that, even if I wanted to. I've got to stick to the rules".

S114 = 2
Stimulus: I am always busy
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being busy?

P: Oh, what was it once? I was knitting, and reading, and having to watch something on the television for my son's benefit to tell him the result, you know [laughs a lot].

R: Can you tell me all the things you remember about it?

P: It would be a race or a match. It would be something like that, but they'd probably been [indistinct]. They had to go to bed, so I said "Well, I'll watch it for you and tell you about it in the morning". So my usual habit was to knit and to read…er, so yes.

R: Can you tell me a little more about that?

P: No, I can't remember a specific, just that particular one.

R: Was anybody else with you at the time?

P: No, the chances are… if my husband had been in I would have delegated him to watch the thing, so he must have been at work. So that makes it probably evening because X had gone to bed.

R: Are you imagining it in your mind now? Can you see yourself?

P: Yes, it was here.

S116 = 1
Stimulus: I am a son
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being a son?

P: [Looking at the picture] It sort of reminds me of being a son. My grandmother, my mother was alive. We didn't have photographs taken like that. Only very rare, that's how I imagine they would be. Not always though.

R: Can you tell me all the things you remember about it?

P: Well, I was with my mother, I mean I was the youngest of a family of four. I think I came along when she was late in life, by the sound of it. That's why I put a bit lonely in there, because I was. But I always got a lot of love from me mother, always.

Wife: She died when he was out in the forces.

P: She did, yes. I always remember my childhood was very happy, even though I felt lonely sometimes, a very happy childhood. When I look round now, some of them round that particular time, their fathers were out of work. My father was a railway policeman so he was always paid every week.

R: Was that in this area? Have you always lived in Yorkshire?

P: Always in Bradford. U**** Street it was. My mother used to feed the nation round that area sometimes.

R: Did the neighbours come in?

P: Yes, yes. I didn't see much of me dad 'cos he worked different shifts, and he got gassed during the war so he suffered with ulcers, stomach ulcers all the time. So I didn't go out with him much, you know [indistinct] 'cos folk talked. I talked to me mum quite often.

Wife: He used to go to the pictures then come home and tell his mum.

P: Yes, I did 'cos I loved the pictures when I was a kid.

R: What pictures? Did you have any favourite actors?

P: Cowboys, oh yes, cowboys. Every Saturday afternoon we used to go down to the er, what we used to call the flea pit. It was the Hippodrome and always had cowboy pictures in there. Always a chase at the end of it so you can imagine what kids {indistinct]. And I always remember on day my mother said "You know they're selling toffee that couple. Don't have any of that 'cos it'll make you ill. "No Mother". So what did I do? I bought it.

R: Did it make you ill?

P: No, did it heck, no! I like to go down the cinema. I did like to play out, really. My mother couldn't get me in, and the one thing I notice today, amongst the youngsters is, they don't have the freedom like we had. When the summer holidays came, me dad bought me a

bike, I always remember it. And me mother used to pack us up, and we used to go out for the day. We didn't come back until night time for tea. We used to go into the woods near us on the bikes, dare devil. We used to go to Otley and Ilkley and all over.

P continued to talk for about his sister on a tandem and his mother using a Canadian washing machine that his father had bought her.

S117 = 1
Stimulus: I am a husband
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being a husband?

P: Four daughters. We struggled in us time. We're alright now. There's one thing, all our daughters have been brilliant to us. They have, they all look in on us. And most of their husbands are as well.

R: Can you tell me all the things you remember about it?

P: I can't, there's that many.

S118 = 1
Stimulus: I am a fan of caravanning
R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of caravanning? Can you tell me all the things you remember about it?

P: All my memories are special, when my children were little. We used to go on holidays.

R: Can you tell me a little more about it?

P: I just enjoy the freedom of it.

R: Did you stay in this country or go abroad?

P: I've just stayed in this country, but I'd like to go abroad in one.

R: Is there any one place that stands out as being your favourite place?

P: Er, long pause.

R: Do you like being by the coast or inland?

P: Either. When we go by the coast I can always walk down the country lanes as well.

R: And the weather, is it usually good for you?

P: It's always been at springtime. Scenic walks.

S119 = 3
I am a family person
R: Please can you look at this picture again. Can you tell me about a memory that you have that is about being with your family?

P: I think our 50th wedding anniversary.

R: Can you tell me all the things you remember about it?

P: It was such a happy day, actually. [Wife] was starting Alzheimer's. She knew everything about the party. When we had our wedding reception, when we first got married. We had the 50th wedding anniversary in the same place. It was lovely.

S120 = 2

Stimulus: I am a son

R: Please can you look at this picture again. Can you tell me about a memory of a particular memory that you have of being a son? Can you tell me all the things you remember about it?

P: My mother used to drive me mad. I used to go and visit. "Do you want a cup of tea son?" "No thanks". "Go on, have a cup of tea". "Alright, thanks, okay, I'll have a cup of tea, thank you". Ten minutes later she'd come out of the kitchen. I'd say "Where's my cup of tea?" She'd say "Do you want a cup of tea son?" I'd say "Forget it", and swear under my breath, you know.

R: Can you tell me a little more about her?

P: She'd been through a rough time. You know, the war years and what have you. She'd been bombed by the Americans, so it didn't help. There was a bit of shrapnel still in her arm. That's another thing, I really didn't appreciate what she'd been through. Same with my dad. He was ill at the time and died when I was 14. He was only 53 but the war had messed him up, like it did with a lot of people. We just take it for granted nowadays, you know. At least at this late stage I can appreciate what they went through, and er, understand it, and have compassion for those people.

Appendix XXII: Study 2 Protocol

Research Protocol
Validating an Objective Measure of Self in Dementia

1. Introduction
Self is considered to be a vital and enduring feature of all human beings and preservation of self is fundamental for wellbeing (Fazio, 2008). It is believed that cognitive impairment and memory loss associated with dementia lead to change in self and this has been reported as one of the most feared consequences of dementia (Corner & Bond, 2004). These fears are based on the assumption that because people have difficulty remembering recent and past events they also lose their sense of self (Cohen & Eisdorfer, 2001). However, evidence suggests that impairments relate to the accessibility of these memories rather than degradation of the memories themselves. This is supported by research which has shown that sense of self can be retained by people with dementia even when cognitive impairment is severe (e.g. Caddell & Clare, 2013; MacRae, 2010; Sabat & Harre, 1992).

The aim of this research project is to validate an objective measure of self that can be used with people living with dementia. There is currently no suitable measure of self for people with dementia; existing cognitive measures are not suited for people who may have language impairments or difficulties with self-expression due to cognitive impairment. Furthermore, they are typically administered under strict experimental conditions which are inappropriate. Since maintenance of self is central to good quality person-centred care, a new measure of self will enable the evaluation of interventions designed to enhance the care of people with dementia, and can be used as a basis for further research involving self and dementia.

The new Measure of Self is based on the framework of self shown in Figure 1 below. This framework was developed following a literature review and consultation with international experts. The framework demonstrates that self is multifaceted; it makes links between disciplines that have sought to understand and identify components of self, but have tended to focus on specific aspects. Figure 1 illustrates the different constituents of self within the framework; the red rectangles present different theoretical approaches reflected in the framework; the blue rectangles represent the components of self that have been investigated in association with these different theoretical approaches.

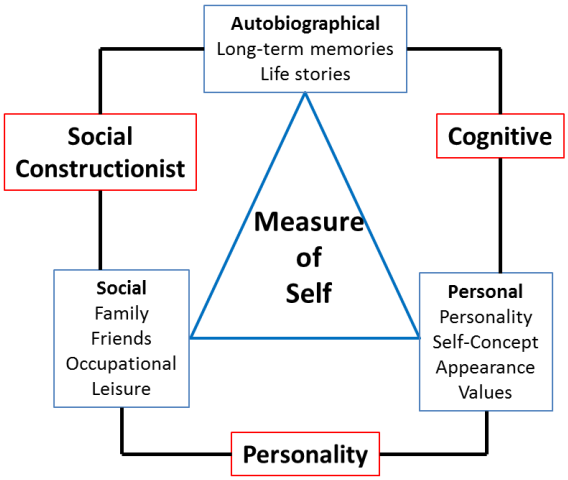


Figure 1: A conceptual framework of self

The materials which form the current Measure of Self have been adapted from three well established quantitative measures of self chosen to reflect each of the components in the

conceptual framework. They are: the 'Self and Identity in Dementia Questionnaire' (SIDQ, Cohen-Mansfield et al, 2000), 'The Twenty Statements Test' (TST, Kuhn & McPartland, 1954) and the 'Tennessee Self-Concept Scale II' (TSCS-II, Fitts & Warren, 1996). The SIDQ covers the 'Social' component of self, the TST and TSCS-II cover the 'Personal' component, and all draw on 'Autobiographical' memories and life stories. These measures draw on social constructionism, personality theory and cognitive psychology. However, in their current form, the cognitive demands involved with completing these measures mean they would not be suitable for use with a population of people living with dementia. For example, the TSCS-II consists of 82 statements which all must be considered and rated, and the TST requires deliberate memory recall which can be difficult for people with dementia (these tests are described more fully below).

The new measure of self incorporates adaptations to make these measures suitable for use with people with dementia. Elements have been selected from each of the measures according to recommendations from a panel of expert advisors in the fields of self and dementia (Prof Steve Sabat, Prof Pia Kontos, and Dr Clare Rathbone). The selected tasks and activities have been adapted, for example, visual images have been developed to use as stimuli to prompt self-descriptions instead of free recall, and observational methods have been designed to aid categorisation of participant's responses to the stimuli.

Specifically, the new Measure of Self comprises a range of illustrated statements (stimuli) relating to the different aspects of self (as per Figure 1). The stimuli are divided into three sets relating to 'Activities' (44 images), Traits and Physical Characteristics' (27 images), 'Relationships and Occupations' (13 images). Participants are asked to match the stimuli to three response cards: 'Just like me', 'A bit like me', 'Not at all like me'. The measure takes approximately 30 to 40 minutes to complete.

The current research project is part of a PhD studentship with the overall aim of producing a measure of self for people with dementia. It is being conducted in two phases; first, a pilot study which has established the appropriateness of the materials and administration of the measure for use with people with *mild to moderate* dementia. Second, the current phase, for which we are seeking ethical approval, is a validation study to (i) establish the reliability and validity of the measure, and (ii) confirm that it can be used with people with *moderate to severe* dementia. It is important to include this population because they will be recipients of interventions that the Measure of Self is intended to evaluate.

2. Aims of the current study

1. To validate the measure of self by establishing test-retest reliability and convergent validity.
2. To confirm whether the test can be used with people with *moderate to severe* dementia.

2.1 Study Design

The Measure of Self will be validated by assessing reliability and validity with two groups of participants:

1. A group of people with dementia.
2. A control group of age-matched adults with no memory impairment.

Reliability will be assessed by test-retest reliability. The Measure of Self will be carried out by all participants on two separate occasions (Time 1 and Time 2), two weeks apart. This time scale is based on a validation study investigating awareness in people with dementia by Parrao et al (2016) who developed a structured interview to assess insight and judgement in dementia.

Validity will be assessed by convergent validity. The measure of self will be compared with two 'gold standard' measures that investigate self-concept and identity (TSCS-II and TST). In recognition of the fact that the gold standard measures have not been adapted for people with dementia only

the control group will be asked to complete the gold standard measures at Time 1, as shown in Figure 2.

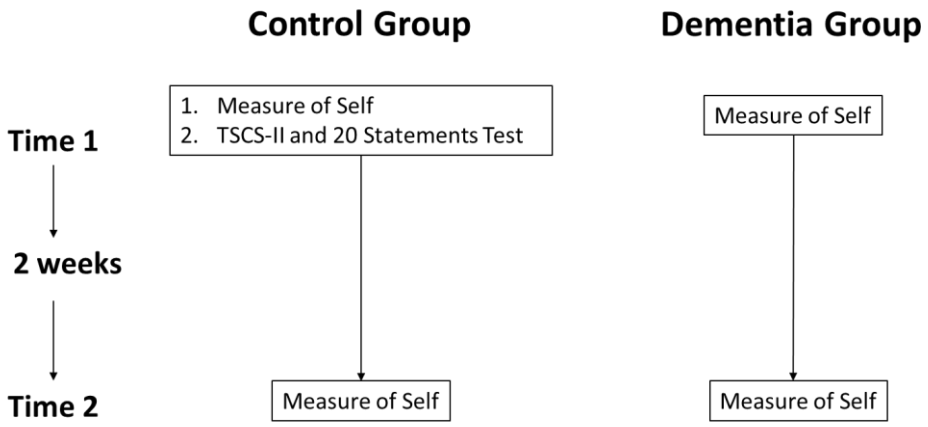


Figure 2: Administration of tests for test-retest reliability and convergent validity

3. Methods

3.1 Participants

Sixteen people with dementia and 16 age-matched people without dementia will be recruited to form a dementia group and a control group. This number is based on a study by Clare et al (2002) who developed and validated a memory awareness rating scale for use with people with dementia. Clare et al conducted their study with two groups of 12 participants. For this study, we will aim to recruit two groups of 16 people to account for possible dropout at Time 2.

Inclusion criteria for the group with dementia will be:

- Adults with a formal diagnosis of any type of dementia who are residents of care homes or who attend dementia support groups and/or day centres.
- English-speaking and able to comprehend written and/or spoken words and pictures.
- No significant hearing impairment (with hearing correction if required).
- No significant visual impairment (with correction if required).

There will be no other exclusion criteria. This study will include all participants who meet the criteria; i.e. with and without capacity to consent.

In order to be able to confirm whether the test can be used with people with *moderate to severe* dementia as well as those with mild dementia, the researcher will aim to recruit people with mild dementia and people with moderate to severe dementia (see definitions below).

Inclusion criteria for the control group will be:

- Adults aged over 65 years of age with no objective memory impairment (>82 on ACE-III).
- English-speaking and able to comprehend written and/or spoken words and pictures.
- No significant hearing impairment (with hearing correction if required).
- No significant visual impairment (with correction if required).

Prospective participants with dementia will be identified and recruited via dementia support groups, and care homes in the Leeds and Bradford areas. Participants for the control group may be partners, relatives or friends of residents of care homes/attendees of support groups. Potential sites have been identified by the researcher. We have contacted 3 care homes and 3 support groups who have expressed an interest in supporting the study. The researcher will discuss the purpose and requirements of the study and participant inclusion criteria with support group and care home staff. Staff members will be asked to display advertising posters and will be given leaflets explaining the project to hand out to people with dementia, and their partners, relatives, or friends of people as appropriate.

People who would like to find out more about the study will be asked to contact the researcher directly (contact details will be on the posters and leaflets), ask a relative or friend to do this for them, or tell staff or managers of their interest. They will also be asked to complete an expression of interest form indicating that they are happy for their personal contact details to be passed on to the researcher so that they can be contacted about the study.

3.1.1 Background Information

Initially, demographic data for participants in both groups will be collected; specifically, date of birth, gender and level of education. In addition, the 4-item Global Depression Scale (GDS4, Shah et l, 1997) will be completed with all participants. The GDS4 is a self-assessment tool that screens for depression in older adults. The scale takes about one minute to administer, with a score of 2 to 4 indicating possible depression. It is known that depression can impair memory and self-esteem (Williams et al, 2007), therefore a person's mood at the time of completing the Measure of Self will be relevant to how they perform on the measure.

For those with dementia, one of the following measures will be completed to provide information about cognitive functioning:

- The Addenbrooke's Cognitive Examination III (ACE-III, Hseih et al, 2013)
- The FAST Scale of functional abilities (Reisberg, 1988)

The ACE-III will provide information about the cognitive abilities of participants to help provide an understanding of how people with different cognitive abilities respond to the Measure of Self. It measures memory, attention, language and visuospatial functions, which are all relevant to completing the Measure of Self. The ACE-III is suitable for use with people over 50 years of age and has a maximum score of 100. Higher scores indicate better cognitive functioning, with scores of 82-88 suggesting dementia. It will take 15 to 20 minutes to complete. If participants are unable to complete the ACE-III (e.g. due to difficulties with cognition or attention), the FAST Scale will be completed by consulting a relative or member of staff who knows the participant well. The FAST scale describes 7 stages of dementia related to physical and cognitive abilities. Stage 1 indicates no cognitive decline, stage 7 indicates severe dementia.

The ACE-III will act as a screening tool for members of the control group. If a control participant has a score of less than 82 (out of 100), indicating cognitive impairment the researcher will indicate that they do not meet the requirements of this study. In this instance the participant will be thanked for their time and contribution and the interview will be bought to a close. The researcher is not qualified to diagnose cognitive impairment. The information sheet for control participants will state that scores outside set ranges will mean that they are not suitable for completing further measures. The researcher will offer leaflets outlining sources of information and support about cognitive or memory problems to all participants for them to keep if they wish.

3.2 Procedure

All participants will complete two visits at two time-points (as identified in Figure 2). The demographics and neuropsychological measures will be completed in the first session as described above. Participants will also be required to complete the Measure of Self on both occasions.

Additionally, the control group will complete the two 'gold standard' measures (TST and TSCS-II) at Time 1 only. In the control group the administration of the Measure of Self and the gold standard measures will be counter-balanced, i.e. 10 people will perform the Measure of Self first, and 10 people will perform the gold standard measures first.

3.2.1 Measure of Self

The measure of self consists of 3 phases (see Appendix 1 for a more detailed description of the administration procedures):

1. Practice phase
2. Matching phase

3. Sorting and memories phase

1.The practice phase will ensure that participants are able to see the stimuli clearly and understand how to place the stimuli next to cards indicating how much like them they are ('Just like me', 'A bit like me', 'Not at all like me'). The three response cards (e.g. Just like me, a bit like me, not at all like me) will be placed on the table in front of a participant. The participant will be presented with 3 stimulus cards one at a time and asked to place the stimulus card next to the response card that best represents how like themselves the stimulus is. No data will be recorded during this phase.

2. The matching phase will require participants to place each stimulus in front of one of the response cards according to how like themselves they think each stimulus is. In this phase participants will match 84 stimuli from three sets of stimuli (Activities, Traits and Physical Characteristics, and Relationships and Occupations). The stimuli are presented on A4 size cards and are presented as colour photographs representing each activity, characteristic, relationship etc. For example, the stimulus of golf as a hobby is one of the 'Activities'. Participants will respond by verbally indicating, placing or pointing at which ever of the 'like me' responses is most appropriate.

3. The stimuli chosen as 'just like me' will be used for the Sorting and Memories Phase. The number of stimuli will depend on how many the participants have chosen as 'just like me'. If the participant has not chosen any stimuli as 'just like me' the 'a bit like me' pile will be used. The researcher will present two stimuli at a time placed in front of the participant, side by side. The researcher will ask "If you had to choose one of these activities which would you like to do most", or "Which of these describes you the best?" Looking at the two images, participants will choose which is **most** like him or her. This can be made with a verbal or non-verbal indication. The stimulus that participants identify is "most like" them will be retained and compared with the next image from the pile; this procedure will continue until all the 'just like me' (or 'a bit like me') stimuli have been looked at and a single stimulus remains that will be considered to be the most important self-description. The researcher will then use this stimulus to prompt self related memory (or memories) from the participant. The researcher will ask participants to talk about any details that they can remember from the event, such as people they were with, a specific place, or something that happened to them. Responses will be written on answer sheets that will be identified by participants' ID numbers only. The pilot study demonstrated that the Measure of Self will take from 30 to 40 minutes to complete.

3.2.2 'Gold Standard' measures and procedures

After completing the Measure of Self, at Time 1, the participants in the control group will be asked to complete the two gold standard measures of self: the Twenty Statements Test and Tennessee Self Concept Scale II. These measures have been established as valid and appropriate measures of self for people without cognitive impairment. The Twenty Statements Test (TST) was developed as a means of investigating self-concept by Kuhn & McPartland (1954). This test requires participants to write down 20 statements in response to the question "Who am I?" with the intention of generating statements relating to the current self and drawing on autobiographical knowledge. It is suitable for use by people of all ages, and was validated by McCrae & Costa (1988) with participants ranging from 32 years to 84 years of age. Participants are asked to write down 20 "I am…" statements in the order that they come to mind, without worrying about importance or logic. For example, "I am a cricket enthusiast; I am a father". Typically, there is no time constraint as participants are asked to stop when they have written 20 statements.

The Tennessee Self Concept Scale: Second Edition (TSCS-II, Fitts and Warren, 1996) measures three components of self-concept (behaviour, satisfaction and identity) over 5 domains (physical, personal, family, moral and social). It is a written questionnaire consisting of 82 descriptive statements (for example "I am an honest person") that are rated for self-descriptiveness on a 5-point Lickert true/false scale (5 = 'always true' to 1 = 'always false'). It is suitable for people aged between 13 and 90 years, taking between 10 and 20 minutes to complete. Fitts & Warren (1996) reported strong internal consistency (0.81 to 0.95) and strong test-retest reliability (0.62 to 0.82).

Materials: The materials for the TST and TSCS-II will be the same as those used by Addis & Tippet (2004) who administered the tests to a group of 20 people without dementia, age range 65 to 88 years. For the TSCS-II, only the 'Identity' component consisting of 21 statements was used. The method of presentation was adapted for ease of use with older adults; instead of a written questionnaire, the statements were presented individually on laminated cards with the 5-point true-false scale also written on each card.

Administration: For the TST, following Addis & Tippet (2004) participants will be asked to give their responses verbally and these will be written down verbatim by the researcher until 20 responses have been given. The test will be scored according to the total number of statements generated and the numbers of abstract and concrete statements, for comparison with the 'strength' and 'quality of identity' scores of the Measure of Self.

For the TSCS-II, following Addis & Tippet (2004), the researcher will read aloud the descriptive statements at the same time as showing the participant the printed laminated card. The participants will be asked to say how true or false they think the statements are with regard to themselves, and responses will be written down by the researcher. The sum of all the responses will yield a 'strength of identity' score that will be compared with the Measure of Self.

The time required to complete the gold standard measures will be no more than 30 minutes. If participants in the control group feel that they are unable to complete both the Measure of Self and the gold standard measures on a single occasion, the researcher will arrange to visit a second time, as close as possible to the administration of the first measure at Time 1.

3.2.3 Finishing the interview and debriefing

The researcher will spend a few minutes at the end of the interview talking to and thanking participants, and encourage them to ask questions if they wish to know more about the research study.

4. Data Analysis

Results will be analysed using SPSS Version 23. Scores indicating strength, complexity and quality of self will be derived from the Measure of Self. Level of detail in memories recalled by participants without verbal impairment and level of interest score for participants with verbal impairment will also be calculated.

Results of the Measure of Self from the group with dementia and control group, and the outcome scores for the gold standard tests for the control will be analysed using 2x2 ANOVAs, to compare the results from Time 1 and Time 2 and between groups. For reliability to be demonstrated there should be no significant effect of time. Convergent validity will be assessed by Pearson's correlations on the results from the control group only to compare extent to which the Measure of Self correlates with the gold standard measures. For validity to be demonstrated there should be strong ($r>.7$) correlation between the measures.

Results from the group with dementia will be divided into two sub-groups (people with mild dementia and people with moderate to severe dementia, based on ACE-III/FAST scores) to determine reliability for people with different levels of ability. Depending on the numbers within the sub groups parametric or non- parametric comparisons of means at T1 and T2 will be reported.

6. Ethical Considerations and Consent

6.1 Informed consent

This project will recruit participants who have been diagnosed with dementia and therefore the consent process will take into account the requirements of the Mental Capacity Act (2005). This will ensure that potential participants are free from any feelings of coercion or undue influence from the researcher. It is essential to obtain informed consent before any person takes part in a research study, and this issue is especially important for people with dementia who may have communication difficulties that impair their ability to express any concerns about taking part. This

research study will adhere to principles outlined in the Declaration of Helsinki (World Medical Association, 2008). These principles stipulate that the wellbeing and dignity of participants take priority in research studies.

In accordance with the Mental Capacity Act (2005) the researcher will identify:

- Whether the participant understands the information about the study.
- Whether they can retain the information.
- Whether they are able to make a balanced decision regarding participation.
- Whether they are making the decision of their own free will.

The researcher will arrange to visit all prospective participants who have contacted the researcher directly, or via a member of staff, or family member, at a place and time convenient to the participant. The researcher will give prospective participants an information sheet describing the study. There will be information sheets specifically for the group of people with dementia, and for the control group. The information sheets will have two formats; one consisting of written words only, the other will have pictures and fewer words. This latter version will be shown to participants who have difficulty with reading comprehension. The researcher will assist participants, as required, with understanding the information sheet.

As well as details of the study, and what is required of participants, ethical requirements such as confidentiality, right to withdraw and who to ask for further information will be discussed. Prospective participants will be able to keep the information sheet and take it away to help them consider whether or not to take part in the study. A participant will be free to consent to take part during this initial discussion or take time to consider participation. They will be encouraged to talk about the study with family or friends before making the decision. The researcher will contact the prospective participants again after 48 hours, or later if they wish, to enable them to ask questions about the study.

During the consent process the researcher will follow principles advocated by Dewing (2002) who stresses that the consent process must be a meaningful and informative process that takes prospective participants seriously. For participants with dementia the researcher will judge their capacity to make a decision about taking part in the study, with reference to the four principles listed above. The researcher will go through the information sheet with the participant to ensure that the participant understands it, and the researcher will answer any questions about it. The researcher will judge if the person is able to retain the information and make a balanced decision to take part, without feeling under any pressure to do so. Participants who are able to give informed consent will be asked to sign the study consent form. The researcher will similarly ensure that participants in the control group fully understand the requirements of the study before asking them to sign the consent form.

6.2 Participants who do not have capacity to consent

An important feature of this validation study is that it should include people without capacity in order to demonstrate that the new Measure of Self can be used with people living with all stages of dementia. If a participant does not have the capacity to consent at the recruitment stage a relative, senior staff member, or group organiser, who knows the participant well will be asked to identify a personal consultee who can be consulted about the proposed participant's wishes. A letter, information sheets about the study and role of a personal consultee and consent forms will be sent to prospective consultees. The letter will be given directly to the consultee by the researcher or a member of staff if they are regularly present in the service setting or will be sent by post from the service setting, as the researcher will not have permission to receive and store their personal contact details. If the letter is given in person, the staff member or researcher will ask the potential consultee if they are willing to complete a consent to be contacted form and have their details kept by/passed onto the researcher for the purposes of sending out reminder letters and future correspondence. If the prospective consultee agrees to act in this role, the researcher will go

through the information sheet with them to ensure they understand their role. They will be asked to sign the personal consultee declaration form stating what they think their relative or friend's wishes would be if they had capacity. This form will be returned by post to the researcher in a pre-paid envelope. The researcher will use this information to decide if the prospective participant would agree to take part in the study.

The researcher will wait two weeks for a response to the initial letter. If there is no response, a reminder letter will be sent to the potential consultee from the researcher or via the service setting to check that they have received the information. If there is still no response after a further week the group organiser or care home manager will be asked to suggest an appropriate person who could be approached to act as the person's nominated consultee. This may be a member of care staff who has known the person well for some time and has no direct involvement or vested interest in the research study. If the person agrees to consider acting as a nominated consultee the researcher will meet with them to explain what would be expected of them. They will be given the opportunity to discuss the study with the person with dementia and their relatives/friends (where applicable). They will be asked to use that discussion to provide advice to the researcher about the person's wishes with regard to participation in the study, based on what the nominated consultee believes the person would have wished if they were able to make a decision. If the person agrees to act as a nominated consultee they will be asked to sign a nominated consultee declaration form, and they will also be asked to contact the researcher if they feel that the participant's circumstances have changed in such a way that the participant may no longer wish to take part in the study.

6.3 Right to withdraw

An important feature of the consent process is that the participant has the freedom to continue or withdraw from the study, and it must be clear that the researcher does not exert any influence over the participants to remain in the study. The researcher will ensure the continued welfare of the participants, and will always be aware of verbal and nonverbal behaviour which indicates that a participant may wish to withdraw.

6.4. Confidentiality

Confidentiality requires that a participant cannot be identified by any means in the data that is collected by the researcher. No participant will be identified by name or association. Each participant will be assigned a unique identification code to ensure anonymity. All paper-based research records will be stored in locked filing cabinets at the University of Bradford which only the researcher can access. Electronic data records will be stored on password protected computers at the University of Bradford, for up to 5 years. Only minimum identifiable data needed for administration purposes will be collected or recorded and only the student and her supervisors will have access to identifiable data.

6.5 Risks and benefits

There should be minimal risk for participants. However, it is possible that participants may remember unhappy events and become distressed. If this happens the researcher will ask the participant if they would prefer to move on to another question, or take a short break. Also, if a participant says he or she feels tired, or show signs of fatigue, the researcher will ask if they would like to take a break. After the break the participant will be asked if he or she would like to continue, or prefer to stop and complete the interview later that day or on another day, or withdraw from the study. If this is the case they will be allowed to do so, and need not give reasons for this. If the researcher has any concerns about the care and welfare of participants, or observes bad practice, she will raise these with her supervisors in order to determine the best approach in relation to the presenting situation.

There are no direct benefits to participants but there may be satisfaction in feeling that they are contributing to a research study that has the potential to help others in the future.

References:[As Study 1 protocol]

Appendix XXIII: Study 2 IRAS Approval Notification

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT
Telephone: 0207 104 8081

27 June 2017

Mrs Rosemary Bradley
PhD Research Student
University of Bradford
School of Dementia Studies
University of Bradford
Richmond Road
BD7 1DP

Dear Mrs Bradley

Study title:	**Developing An Objective Measure of Self for People Living With Dementia**
REC reference:	**17/YH/0176**
IRAS project ID:	**212033**

The Research Ethics Committee reviewed the above application at the meeting held on 20 June 2017. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Mental Capacity Act 2005
I confirm that the Committee has approved this research project for the purposes of the Mental Capacity Act 2005. The Committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Conditions of the favourable opinion
The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

1. The following amendments to the Consultee Declaration Form are required;
    a. “I agree...” in Clause Three needs to be amended to “I understand…”
    b. Clause Five needs to be amended to read “I believe that the prospective participant would want to take part in the study.”
    c. The Participant Information Sheets need to be revised to ensure that participants are given consistent information about the time taken to complete the questionnaires. The Committee recommended that the Information Sheets stated that completion of the questionnaires could take up to sixty minutes.

    The Committee recommended that you consider excluding those who do not speak English as a first language.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

17/YH/0176 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely
pp

Dr Janet Holt
Chair

Appendix XXIV: Study 2 Posters/Leaflets

[Control Group]

Introducing a new study called…

The Measure of Self

Who are we looking for?

- **We are looking for volunteers who are over the age of 65 who would be willing to talk to a researcher about sense of self. This will require you to complete three measures of self and identity, and two questionnaires about your memory, and mood.**

What would you have to do?

- **You will be invited to take part in a study that is developing a new measure of 'self'.**
- **You will be asked to complete a questionnaire about your memory that will indicate if you are eligible to take part in the study.**
- **If you are eligible you will be asked to complete three measures that will ask how you describe yourself.**
- **This will take the form of two interviews that will last up to one hour, on two occasions two weeks apart. On the second occasion you will only be asked to complete one measure. You will also be asked about your mood on each occasion.**
- **A researcher will visit you somewhere that is familiar to you to carry out the interview.**

What is the study about?

People with memory problems may have difficulty recalling recent and past events which can affect a person's sense of self and identity. Research has shown that good quality care can stop this happening. The purpose of my study is to develop a measure of self that can be used by researchers in the future who are carrying out studies about care.

If you would like to take part in the study please contact me,
Rosemary Bradley, at the University of Bradford:

Tel: 01274 236377

Email: R.J.Bradley@student.bradford.ac.uk

[Dementia Group]

Introducing a new study called…

The Measure of Self

Who are we looking for?

- **We are looking for volunteers who have problems with their memory and would be willing to talk to a researcher about themselves.**

What would you have to do?

- **You would be invited to take part in a study that is developing a new measure of 'self'.**
- **You will be asked to answer some questions about your memory first.**
- **You will be asked to answer some questions about how you describe yourself on two occasions, two weeks apart.**
- **These will take the form of interviews that will last about 45 minutes. You will also be asked some questions about your mood on each occasion.**
- **A researcher will visit you somewhere that is familiar to you to carry out the interview.**

What is the study about?

People with memory problems may have difficulty recalling recent and past events which can affect a person's sense of self and identity. Research has shown that good quality care can help support a person's sense of self. The purpose of my study is to develop a measure of self that can be used by researchers in the future who are carrying out studies about care.

If you would like to take part in the study please contact a member of staff or Rosemary Bradley, at the University of Bradford:

Tel: 01274 236377

Email: R.J.Bradley@student.bradford.ac.uk

Appendix XXV: Study 2 Information Sheets

[Control Group]

PhD Research Study: The Measure of Self
Participant Information Sheet

Who is carrying out this study?
My name is Rosemary Bradley and I am studying for a PhD at the University of Bradford.

What is my study about?
People with memory problems often have difficulties in recalling recent and past events. This can affect a person's sense of self or identity but research has shown that good quality care can help to stop this happening. One challenge for researchers is that we do not have any ways to measure self or identity in people with memory problems. The purpose of my study is to develop a new measure of self for people with memory problems. I hope this will be used by researchers in the future when carrying out studies about care.

Why am I inviting you to take part?
I am seeking people who are over 65 years of age with no memory problems to take part in the research study so that comparisons can be made between people without memory problems and people who have memory problems.

What will I ask you to do?
Firstly, I will ask you to complete a questionnaire about your memory and other aspects of thinking It should take about 15 minutes to complete. There is a set range of scores that indicate who is eligible to take part. If your score falls into this range then I will be able to include you in the rest of the study. I will then ask you to complete the Measure of Self on two occasions, approximately two weeks apart. On the first occasion I will also ask you to complete two other measures of self and identity that are already being used in research studies. This will help me check that the new measure is a reliable way of measuring self and identity.

For the Measure of Self I will show you some pictures that will help you tell me about yourself, such as:

- How you describe yourself.
- Activities you do now and things you used to do.
- Things that you remember doing with other people.

There will be no right or wrong answers. I am only interested in what you can tell me about yourself, and I hope that you will find this interesting and enjoyable.

The other two tests are called the 'Twenty Statements Test' and the 'Tennessee Self Concept Scale'. For the Twenty Statements Test I will ask you to think of twenty ways of describing yourself. For the Tennessee Self Concept Scale, I will show you 21 ways of describing self and identity and ask how true or false they are for you.

I will also ask you four short questions about your mood after the Measure of Self on both occasions.

Will what you say be confidential?
Yes. I will write down what you say but I will not use your name. I will always use a special code instead of your name. If you say anything that you would prefer me not to write down just tell me and I will not do so. If I have already written it down I will make sure it is deleted from the answer sheet.

The only other people who will see your answers are my PhD supervisors. I will only keep the information until I have finished writing about my study which will be no more than 5 years from now. This will be saved securely on a password protected computer in accordance with the Data Protection Act 1998. After that all the information you have given me will be destroyed. I may use some of the things you tell me in my reports, but I will not use your name, and I will change any details that might mean other people could recognise who said them.

How long will the interviews take?
The Measure of Self should take about 30 minutes, and the two self and identity tests also about 30 minutes. We can take breaks if you get tired or finish them on another day.

Are there any risks in taking part in my study?
I do not expect there to be any risks, but if you think of anything that upsets you while I am asking questions you can take a break and we can decide if you would like to continue. You can stop at any time and do not have to explain why. If you do not want your data to be used it will be deleted.

Will travel expenses be reimbursed?
Yes, if you incur any travel expenses by taking part in this study they will be reimbursed in full. I will be able to visit you at home if you prefer.

What should you do if you would like to help with my study?
You can tell me now, or take some time to think about it. I will contact you in a day or so to find out if you would like to take part, or you can take longer to decide if you wish. If you decide to take part I will visit you again and ask you to sign a consent form. I will then arrange a time to meet with you again to carry out the Measure of Self and the two other tests. When we have completed these I will arrange to visit you again after two weeks to complete the Measure of Self for the second time.

What will happen to the information you give me?
I will use it to show that the Measure of Self is reliable and so can be used by other researchers to use with people who have memory problems. I will write a report that will form part of my PhD thesis and write articles for academic journals. I will also talk about my findings at conferences and with other researchers and people with dementia.

If you would like more information, please contact me at the University of Bradford (or ask someone else to do so on your behalf):

Rosemary Bradley

Tel: 01274 236377
Email: R.J.Bradley@student.bradford.ac.uk

Thank you for reading this information sheet.

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not wish to speak to the researcher, you can contact:

Ms Tamsin Holt
Title: Head of Research Support
Email:nhs-ethics@bradford.ac.uk
Telephone: 01274 2360000

[Dementia Group – text version]

UNIVERSITY of BRADFORD

PhD Research Study: The Measure of Self

Participant Information Sheet

Who is performing this study?

My name is Rosemary Bradley and I am studying for a PhD at the University of Bradford.

What is my study about?

People with memory problems often have difficulties in recalling recent and past events. This can affect a person's sense of self or identity. Other people often assume that those who have memory problems lose their sense of self and identity as their memory gets worse. However, research has shown that good quality care can stop this happening. One challenge for researchers is that we do not have any ways to measure self or identity in people with memory problems.

The purpose of my study is to develop a new measure of self for people with memory problems. I hope this will be used by researchers in the future when carrying out studies about care.

Why am I inviting you to take part?

I am seeking people with memory problems who are willing to talk to me about themselves. I understand that you have memory problems and may be willing to take part.

What will I ask you to do?

I will show you some pictures that will help you tell me about yourself, such as:

- How you describe yourself.
- Activities you do now and things you used to do.
- Things that you remember doing with other people.

I will show you some pictures to help you remember things from your past. There will be no right or wrong answers. I am only interested in what you can tell me about yourself, and I hope that you will find this interesting and enjoyable.

In order to show that the measure is reliable I will have to ask you to do it on two occasions, two weeks apart, so that I can compare the results. Again there will be no right or wrong answers, and it will not matter if you tell me something differently on the second occasion.

Will I ask you to do anything else?
Before we start the Measure of Self the first time I will ask you if you are willing to answer some questions about your memory. When we have finished the Measure of Self I will ask you four questions about your mood.

Will what you say be confidential?
Yes. I will write down what you say but I will not use your name. I will always use a special code instead of your name. If you say anything that you would prefer me not to write down just tell me and I will not do so. If I have already written it down I will make sure it is deleted from the answer sheet.

The only other people who will see your answers are my PhD supervisors. I will only keep the information until I have finished writing about my study which will be no more than 5 years from now. After that all the information you have given me will be destroyed. I may use some of the things you tell me in my reports, but I will not use your name, and I will change any details that might mean other people could recognise who said them.

How long will the interviews take?
Probably about 45 minutes for the Measure of Self and 15 minutes for the memory questions. We can take breaks if you get tired or finish them on another day.

Are there any risks in taking part in my study?
I do not expect there to be any risks, but if you think of anything that upsets you while I am asking questions you can take a break and we can decide if you would like to continue. If you experience any problems, or feel uncomfortable at any time, tell me and I will stop immediately. You can stop at any time and do not have to explain why. If you do not want your data to be used it will be deleted.

Will travel expenses be reimbursed?
Yes, if you incur any travel expenses by taking part in this study they will be reimbursed in full.

What should you do if you would like to help with my study?
You can tell me now or take some time to think about it, and talk it over with your family or friends if you wish. I will come back to see you in a day or so to find out if you would like to take part, or you can take longer to decide if you wish. You can keep this sheet as a reminder, and ask me some more questions if you have any. If you decide to take part I will ask you to sign a consent form. I will explain what the consent form means and make sure you are happy to sign it. I will then arrange a time to see you again in the next day or so to ask you to complete the Measure of Self.

What will happen to the information you give me?
I will use it to show whether the Measure of Self is reliable and so can be used by other researchers and health practitioners with people who have memory problems. I will write a report that will form part of my PhD thesis and write articles for academic journals. I will also talk about my findings at conferences and with other researchers and people with dementia.

If you would like more information, please contact me at the University of Bradford (or ask someone else to do so on your behalf):

Rosemary Bradley

Tel: 01274 236377
Email: R.J.Bradley@student.bradford.ac.uk

Thank you for reading this information sheet.

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not wish to speak to the researcher, you can contact:
Ms Tamsin Holt
Title: Head of Research Support
Email:nhs-ethics@bradford.ac.uk Tel:01274 2360000

[Dementia Group – pictorial version]

Participant Information Sheet
PhD Study: The Measure of Self

Hello! My name is Rosemary Bradley
I am a PhD student working at Bradford University.
I am carrying out a study about sense of self in people who have memory problems.

I will be performing the study myself but I have supervisors at the university to help me.

I would like to ask you some questions about your memory and mood, and how you describe yourself. I will show you some pictures to help you remember things about yourself.
I will visit you twice to ask you these

I will write down what you tell me but no one else will know what you have told me except my supervisors.

I will ask these questions in a place that is comfortable and familiar to you. If you have to pay travel expenses I will be able to refund them for you.

If you would like to help me with my study I will visit you again.

I will ask you to sign a consent form. I will help you do this and you can have someone else with you if you like.

I will fix a date and time to visit you again to ask you the questions about yourself and your mood. Do not worry if you cannot answer some of the questions. There are no right or wrong answers. This should take about 60 minutes.

I will visit you again after two weeks to ask you the same questions.

If you change your mind at any time you can tell me to stop.

If you feel unwell or uncomfortable at any time you can tell me to stop.

If you would like to know more about the study you can ask someone to contact me at Bradford University:

Rosemary Bradley
Tel: 01274 236377
Email: R.J.Bradley@student.bradford.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Ms Tamsin Holt
Title: Head of Research Support
Telephone: 01274 2360000
Email: nhs-ethics@bradford.ac.uk

Appendix XXVI: Documents for Personal and Nominated Consultees

Documents for consulting with a PERSONAL CONSULTEE

Letter from care home manager to partner, family member or friend

Address
Phone number

Dear [Name]

The [care home] is collaborating with Rosemary Bradley form the University of Bradford in a research project.
The project is called: PhD Study: The Measure of Self.

An important aspect of the research project is that all participants have the choice about whether to volunteer or to refuse to take part. However, some of the residents may not have the capacity to consent because of a condition that affects how they may make some decisions.

You have been approached as you are a relative or friend of a resident of this care home. The researcher would like to discuss with you your views about whether [name] may wish to participate in the research.

I attach some information and forms about the project and ways that you can help.

Please look at this information and complete the forms and return to me using the stamped addressed envelope. If you have any queries please contact [name] on [phone number] to discuss.

Thank you for your interest in the project and taking time to read the information.

Signed (by the manager).

Participant Information Sheet will be attached to this letter.

Additional Information for Personal Consultees

I am intending to recruit participants to this project who may not have the capacity to consent to their participation. This means they may not be able to judge for themselves whether they should like to take part or refuse. The project includes such participants because the members of my research team feel it is important for people with advanced dementia to have the chance of taking part in the research project.

The project has been approved by a [named] Research Ethics Committee. We shall make sure that the project is safe for each participant and does not cause them undue distress. To help with this, I need information from people who have known the participant for some time.

I have approached you because as a partner, relative or friend of a prospective participant in the study, you will have an interest in his/her wellbeing and welfare. I would like to discuss with you whether you think your relative or friend would like to take part. As you have known them for some time, you may be aware of any views they may have about taking part in such a project or whether they have made an 'Advance Decision'. If your relative or friend has made an 'Advance Decision' this is important as it shows that they have already made a decision for themselves. I would like to respect these wishes.

If you think your relative or friend may be interested in taking part in the project, you may be able to tell us about any possible difficulties that they may have. You may also be able to tell us how they may communicate that they want to stop being involved.

When thinking about the wishes of your relative or friend it is important that you set aside your own views about the project. A 'personal consultee' is a partner, relative, or friend of a prospective participant, who provides the researchers with advice.

If you think your partner, relative or friend would be interested in taking part, please complete the attached form and send it back to [name] using the stamped addressed envelope.

If you think your partner, relative or friend would be interested but you are not sure about whether you would like to talk about this with me, please suggest who else could be approached.

If you think your partner, relative or friend would **not** be interested in taking part, it is important to still complete the attached form.

Information about yourself (name, address, telephone number) is in the records held by the [name of care home} team. The care tam will contact you should I wish to speak with you.

Information that you disclose about your partner, relative or friend concerning their participation in the research will be held by the research team. The research team will not know your name, address, or telephone number. When you meet with me, I will talk with you about confidentiality.

The forms you return will be looked at by the research team. The care team will contact you by [date] to let you know whether or not the researcher would like to speak with you and arrange a time for discussion.

If you do not return the form, we will assume that you do not wish to be contacted by the researcher.

If you would like to find out more about the project, please contact Rosemary Bradley on 01274 236377 or email: R.J.Bradley@student.bradford.ac.uk.

Participant ID

Invitation to act as a Personal Consultee

Project Title: PhD Study: The Measure of Self

I think that my partner, relative or friend would **NOT** like to take part in the project	Signed……..
I think my partner, relative or friend may be interested in taking part and I would like to discuss this with the researcher	Signed……..
I think that my partner, relative or friend may like to take part in the project – but I do not want to be consulted	Signed……..

Thank you for completing the form. Please send it in the stamped addressed envelope to the care home manager [name]

Personal Consultee Declaration

Project Title: PhD Study: The Measure of Self

Please initial your confirmation/understanding below

1. I confirm that I have read and understood the Information for Consultees (version….dated….) for the study.
2. I confirm that I have had time and opportunity to ask questions about the study and/or my role as Personal Consultee.
3. I understand the purpose of the project and what the participant's (partner, relative or friend) involvement would be. In my opinion, they would not object to taking part in the study.
4. I understand that participation in the project is voluntary and that my partner, relative or friend would be withdrawn if they do not wish to continue participating and without giving a reason.
5. I understand that if my partner, relative or friend were withdrawn from the project, this would not in any way affect the care or treatment they receive or affect their legal rights.
6. I understand……(other features relevant to the project)

Name of consultee	Date	Signature
Name of the person who has discussed the study and provided me with information	Date	Signature
Principal Researcher	Date	Signature

When completed – one copy to be held in care records, one copy for the Consultee, one copy for the researcher.

Letter from researcher to prospective Nominated Consultee

Address
Phone number

Dear [Name]

The [care home] is collaborating with Rosemary Bradley form the University of Bradford in a research project.
The project is called: PhD Study: The Measure of Self.

An important aspect of the research project is that all participants have the choice about whether to volunteer or to refuse to take part. However, some of the residents may not have the capacity to consent because of a condition that affects how they may make some decisions.

You have been approached as you have been named by the care team as someone who can be consulted on such matters. I would like to discuss with you your views about whether [name] may wish to participate in the research.

I attach some information and forms about the project and ways that you can help.

Please look at this information and complete the forms and return to me using the stamped addressed envelope. If you have any queries, please contact [name] on [phone number] to discuss.

Thank you for your interest in the project and taking time to read the information.

Signed (by the researcher).

Participant Information Sheet will be attached.

Information Sheet for Nominated Consultee

Additional Information for Nominated Consultee

I am intending to recruit participants to this project who may not have the capacity to consent to their participation. This means they may not be able to judge for themselves whether they should like to take part or refuse. The project includes such participants because the members of my research team feel it is important for people with advanced dementia to have the chance of taking part in the research project.

The project has been approved by a [named] Research Ethics Committee. We shall make sure that the project is safe for each participant and does not cause them undue distress. To help with this, I need information from people who have known the participant for some time.

I have approached you because you may be someone who already knows the prospective participant in the study, perhaps working with them as a paid carer. Alternatively you may already have been approached by a care organisation and agreed to act as a Consultee.

If you do know the prospective participant, you may be able to advise us about any possible difficulties they may have in taking part. You may also be able to tell us how they may communicate that they want to stop being involved.

When thinking about the wishes of your relative or friend it is important that you set aside your own views about the project.

If you think the prospective participant would be interested in taking part, please complete the attached form and send it back to me using the stamped addressed envelope.

If you think the prospective participant would be interested but you are not sure about whether you would like to talk about this with me, please suggest who else could be approached.

If you think the prospective participant would **not** be interested in taking part, it is important to still complete the attached form.

Information about yourself (name, address, telephone number) is in the records held by the [name of care home] team.

Information that you disclose about your partner, relative or friend concerning their participation in the research will be held by the research team. The research team will not know your name, address, or telephone number. When you meet with me, I will talk with you about confidentiality.

The forms you return will be looked at by the research team. The care team will contact you by [date] to let you know whether or not the researcher would like to speak with you and arrange a time for discussion.

If you do not return the form, we will assume that you do not wish to be contacted by the researcher.

If you would like to find out more about the project, please contact Rosemary Bradley on 01274 236377 or email: R.J.Bradley@student.bradford.ac.uk.

Participant ID

Invitation to act as a Nominated Consultee

Agreement to act as a Nominated Consultee

Project Title: PhD Study: The Measure of Self

I think that the prospective participant may **NOT** like to take part in the project	I agree with this statement Signed……..
I think that the prospective participant may be interested in taking part and I would like to discuss this with the researcher	I agree with this statement Signed……
I think that the prospective participant may like to take part in the project-but I do not wish to be consulted	I agree with this statement Signed……

Thank you for completing the form. Please send in the stamped addressed envelope to [name].

Participant ID

Nominated Consultee Declaration

Nominated Consultee Declaration
(Version….Date….)

Project Title: PhD Study: The Measure of Self

Please initial your confirmation/understanding below

1. I confirm that I have read and understood the Information for Nominated Consultees (version….dated….) for the study.
2. I confirm that I have had time and opportunity to ask questions about the study and/or my role as Nominated Consultee.
3. I understand the purpose of the project and what the participant's involvement would be. In my opinion, they would not object to taking part in the study.
4. I understand that participation in the project is voluntary and that the participant would be withdrawn if they do not wish to continue participating and without giving a reason.
5. I understand that if the participant were withdrawn from the project, this would not in any way affect the care or treatment they receive or affect their legal rights.
6. I understand……(other features relevant to the project)

Name of consultee	Date	Signature
Name of the person who has discussed the study and provided me with information	Date	Signature
Principal Researcher	Date	Signature

When completed – one copy to be held in care records, one copy for the Consultee, one copy for the researcher.

Appendix XXVII: The Twenty Statements Test

Participant ID: _____ Date: _____

Twenty Statements Test

Ask the participant to complete the sentence "I am:…", using a different word or phrase each time, that he/she believes is true about his/herself. Prompt with types of response, e.g. characteristics, roles, abilities.

1. I am_____

2. I am_____

3. I am_____

4. I am_____

5. I am_____

6. I am_____

7. I am_____

8. I am_____

9. I am_____

10. I am_____

11. I am_____

12. I am_____

13.I am_____

14. am_____

15. I am_____

16. I am_____

17. I am_____

18. I am_____

19. I am_____

20. I am_____

Appendix XXIX: The 21 Item TSCS

21 Identity Items from the Tennessee Self Concept Scale II

(Fitts & Warren, 1996)

The statements will be presented individually on laminated cards with the 5-point true/false scale printed on each card. Participants will be asked to rate each statement for self-descriptiveness, specifically "How well does each statement describe YOU. Please tell me which point on the scale is most like you".

I have a healthy body

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I like to appear neat and attractive

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am an untidy person

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am not a healthy person

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am a well-mannered person

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am an honest person

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am a bad person

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am a weak-willed person

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am a cheerful person

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I have high self-control

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am a calm person and easy to befriend

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am not important

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I can no longer think straight

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am important to my family and my friends

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am from a happy family

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am a friendly person

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am more popular among females

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am more popular among males

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I feel angry towards everybody

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I am not interested in what others are doing

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true

I find it difficult to develop closeness with others

1=always false 2=mostly false 3=partly false and partly true

4=mostly true 5=always true